Law Reform Commission

Withholding or Withdrawing Life Sustaining Medical Treatment

2003

Manitoba
Law Reform
Commission

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Law Reform Commission

Commission de réforme du droit

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WITHHOLDING OR WITHDRAWING LIFE SUSTAINING MEDICAL TREATMENT

Report #109

December 2003

Canadian Cataloguing in Publication Data

Manitoba. Law Reform Commission.

Withholding or withdrawing life sustaining medical treatment.
(Report ; #109)

Includes bibliographical references.
ISBN 0-7711-1530-X

1. Medical ethics -- Manitoba. 2. Medical laws and legislation -- Manitoba. 3. Right to die -- Manitoba. 4. Euthanasia -- Law and legislation -- Manitoba. I. Title. II. Series : Report (Manitoba. Law Reform Commission) ; 109

KEM424.8.E97.M36 2003 344.7127/04197 C2003-96-2001-8

Copies of the Commission's Reports may be ordered from the Publications Branch, Office of the Queen's Printer, 200 Vaughan Street, Winnipeg, MB R3C 1T5; however, some of the Commission's Reports are no longer in print.

The Manitoba Law Reform Commission was established by *The Law Reform Commission Act* in 1970 and began functioning in 1971.

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The Manitoba Law Reform Commission is funded by grants from:

The Government of Manitoba

and

The Manitoba Law Foundation

TABLE OF CONTENTS

Page #

CHAPTER 1 - INTRODUCTION 1
- A. INTRODUCTION 1
- B. SCOPE OF THE REPORT 1
- C. ACKNOWLEDGEMENTS 2

CHAPTER 2 - THE MEDICO LEGAL CONTEXT 3

CHAPTER 3 - THE STAKEHOLDERS AND THEIR INTERESTS 6

CHAPTER 4 - RESPONSES TO THE DISCUSSION PAPER 9

CHAPTER 5 - PRINCIPLES AND POLICIES 11

CHAPTER 6 - THE *PROPOSED "SAMPLE"* POLICY OF THE COLLEGE OF PHYSICIANS AND SURGEONS OF MANITOBA 14

CHAPTER 7 - THE CONTRIBUTION OF OTHER HEALTH CARE BODIES AND INSTITUTIONS 27

CHAPTER 8 - RECOMMENDATIONS 32

APPENDIX A - MANITOBA LAW REFORM COMMISSION DISCUSSION PAPER (June, 2002) 35

APPENDIX B - LIST OF PERSONS, ASSOCIATIONS, AGENCIES AND INSTITUTIONS WHO RESPONDED TO THE DISCUSSION PAPER AND THOSE WHO RECEIVED COPIES OF IT 81

APPENDIX C - *PROPOSED "SAMPLE"* POLICY OF THE COLLEGE OF PHYSICIANS AND SURGEONS OF MANITOBA 92

APPENDIX D - ADVANCED CARE PLANNING PROTOCOL OF THE WINNIPEG REGIONAL HEALTH AUTHORITY 99

EXECUTIVE SUMMARY 106

RÉSUMÉ 109

CHAPTER 1

INTRODUCTION

1. INTRODUCTION

In June 2002, the Manitoba Law Reform Commission released a Discussion Paper entitled *Withholding or Withdrawing Life Sustaining Treatment*[1] (Appendix A). It explores a range of issues relating to end of life medical decision making including:

- the power of modern technology to prolong life beyond its natural end;
- the propriety of providing life sustaining medical treatment which offers no therapeutic benefit and may threaten additional harm;
- the competing interests of patients, physicians and other stakeholders;
- the allocation of ultimate authority for making decisions to withhold or withdraw life sustaining medical treatment; and
- the principles and procedures that should guide the decision making process.

We invited all interested persons and organizations to express their views on the matters raised in the Discussion Paper. We were heartened by the good response. A list of persons, associations and institutions that made submissions to us is found in Appendix B at the end of this Report. These submissions have proved invaluable in providing useful information and relating different experiences and perspectives on these difficult issues. They also indicated avenues of compromise and resolution.

2. SCOPE OF THE REPORT

This Report commences with a description of the medico/legal context in which the issue of withholding and withdrawing life sustaining medical treatment arises. It then identifies the stakeholders and their competing interests; reviews the responses to the Discussion Paper outlining points of consensus and matters of contention; identifies the principles and policies on which the rules and procedures relating to end of life medical decision making should be based; evaluates and comments on the recent sample *Policy of the College of Physicians and Surgeons of Manitoba* on *Withholding or Withdrawing Life-sustaining Medical Treatment* (Appendix C)[2] and, identifies the role of other health care institutions and associations in facilitating and supporting the end of life medical decision making process. It concludes with our recommendations.

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[1] Manitoba Law Reform Commission, *Withholding or Withdrawing Life Sustaining Treatment* (Discussion Paper, June 2002), hereinafter referred to as the Discussion Paper.

[2] College of Physicians and Surgeons of Manitoba, *Submission to the Manitoba Law Reform Commission Re: Discussion Paper on Withholding or Withdrawing Life-sustaining Treatment* (December 2002).

C. ACKNOWLEDGEMENTS

The Commission gratefully acknowledges Prof. Philip H. Osborne of the Faculty of Law, University of Manitoba, who was retained as our consultant to prepare this Report. His assistance in guiding us through the difficult policy issues addressed in this Report was invaluable and we extend our most sincere thanks.

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CHAPTER 2

THE MEDICO LEGAL CONTEXT

The physician/patient relationship has undergone a substantial evolution since the mid-twentieth century from an authoritarian or paternalistic model to a much more equal and participatory one. The paternalistic model of the relationship was marked by the patient's uninformed and unquestioning reliance on the physician's diagnosis and treatment advice and the patient's willingness fully to trust the physician to discharge his or her fiduciary duties and administer health care in accordance with his or her clinical judgment and in the patient's best interests. The late twentieth century witnessed a change in both the expectations of patients and in the clinical practice of most physicians from paternalism towards a more egalitarian and participatory model which emphasizes patients' rights, individual autonomy and personal decision making. The *legal* vehicles which facilitated and supported this change to a more participatory model were the notions of *consent to treatment* and *informed consent to medical treatment*.

Medical treatment without the consent of the patient is an unlawful touching, a battery, the remedy for which is an action for damages. Consent to treatment is not a mere formality. It is an essential prerequisite not only in respect of what medical care may be given, but also to when, where and by whom it will be given.[1] It secures the patient's autonomous power to accept or refuse medical care for any reason.

The doctrine of informed consent was formulated by the Supreme Court in *Reibl* v. *Hughes*.[2] The Court held that physicians are under a legal obligation to volunteer all *material* information relating to their patients' illness and treatment options. Furthermore, they must answer all questions posed by their patients fully, frankly and honestly. This doctrine, which is part of the physician's obligation of care under the tort of negligence, plays a very important role in facilitating the participatory model of the physician/patient relationship. Patients who have reliable information about the nature of their illness, the treatment options, the risks and benefits of those options and the consequences of inaction are in a position to make wise health care decisions in their personal interest.

These legal principles are applicable to all health care decision making including end of life medical decision making. They ensure that patients who face terminal illnesses receive full and complete information about their illness, treatment or palliative care options and prognosis. On the basis of full and complete knowledge they may accept or refuse the medical treatment offered by the physician. The right to refuse treatment includes the right to refuse potentially life saving and life sustaining treatment. Refusal of treatment may be communicated directly to the physician or may be planned in advance by the use of health care directives or the appointment of health care proxies. There is consequently a "right to die" exercisable by the rejection of medical care.[3]

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[1] *Allan* v. *New Mount Sinai Hospital* (1980), 109 D.L.R. (3d) 634 (Ont. H.C.J.), per Linden J., new trial ordered (1981), 125 D.L.R. (3d) 276 (Ont.C.A.).

[2] *Reibl* v. *Hughes* (1980), 114 D.L.R. (3rd) 1 (S.C.C.); [1980] 2 S.C.R. 880.

This emphasis on patients' rights, autonomy and personal control over one's health care has influenced the debate about the physician's role in withholding or withdrawing life sustaining medical treatment. It is suggested by some that the legally recognized "right to die" should be complemented by a "right to life" and that physicians should not be permitted to withhold or withdraw life sustaining medical treatment *without the consent of the patient*. A patient should, it is argued, have a *right* to life sustaining treatment for as long as he or she deems it to be in his or her personal interests. Such a right would, of course, give rise to a correlative *duty* on the physician to provide the treatment requested without regard to his or her ethical and professional assessment of the patient's condition, the nature of the treatment sought, its potential benefit, if any, and the harm that may result from it. Patients would then be in full control of their end of life passage.

To date, no Canadian court has recognized a positive right to life sustaining or life prolonging medical treatment.[4] The case law, which is reviewed in the Discussion Paper,[5] is not authoritative and it is not uniform but it is fair to conclude as a general proposition that the physician has the ultimate power to withhold or withdraw life sustaining treatment *without the consent of the patient*. In exercising that power, there are onerous ethical and legal obligations of consultation, information and discussion the objective of which is to lead to a consensus decision, but where an impasse is reached the physician may withhold or withdraw life sustaining medical treatment. This may appear to be reflective of the discredited authoritarian, paternalistic medical practices of the past but there is reason for caution before entertaining a right to life sustaining medical treatment.

In general medical practice, it is well recognized that physicians have an ethical and professional obligation not to provide medically inappropriate or unethical treatment no matter how insistent the patient may be. There is very little debate about that as a general proposition. Physicians ought not to prescribe antibiotics for viral illnesses, perform therapeutic surgery without clinical indicators of illness or injury or provide monthly physical check-ups for a patient just because that is what the patient wants. It is likely that there is a community consensus that the refusal to provide such treatment is appropriate and the power to do so is appropriately entrusted to physicians. This consensus, however, breaks down in respect of the physician's power to withhold or withdraw *life sustaining* medical treatment. The sanctity and value of all human life, the profound and irreversible consequences of withholding or withdrawing treatment, the highly personalized circumstances of the patient's family, spiritual and cultural life and the patient's fear of losing personal control at the most vulnerable of times explain the emotional and intuitive attraction of the notion of personal autonomy and support for a patient's right not only to refuse life sustaining treatment but also to *demand* life sustaining measures. The allocation of decision making power and the manner in which these decisions shall be made are central to this Report. No resolution can be found without careful consideration of all the competing interests and the answer lies in accommodating those interests in as fair and reasonable a way as possible.

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[3] *Malette* v. *Shulman* (1990), 67 D.L.R. (4th) 321 (Ont. C.A.); *N.B.* v. *Hôtel-Dieu de Québec* (1992), 86 D.L.R. (4th) 385 (Qué. Sup. Ct.). See also, B. Sneiderman, J.C. Irvine and P.H. Osborne, *Canadian Medical Law: An Introduction for Physicians, Nurses and other Health Care Professionals* (3rd ed., 2003) c. 19, 423-457.

[4] A variety of potential arguments for a right to treatment based on the *Charter of Rights and Freedoms*, federal and provincial legislation and relevant literature to this issue are explored in the Discussion Paper at pp.12-18. None of this legislation speaks directly to the point at issue in this paper. Consequently, the discussion is inconclusive and speculative.

[5] Discussion Paper, Chapter 2.

CHAPTER 3

THE STAKEHOLDERS AND THEIR INTERESTS

There are many individuals and institutions affected by decisions to withhold or withdraw life sustaining medical treatment. They include physicians, other members of the health care team, health care institutions, patients, substitute decision makers for patients who lack capacity,[1] family members, the public, members of vulnerable groups and government. A brief consideration of those interests will reveal the difficulty in reconciling them.

Physicians carry a great deal of authority and responsibility for the provision of health care. They are regulated by the ethical and professional standards of the College of Physician and Surgeons of Manitoba and are subject to stringent fiduciary obligations to their patients. Their primary concern is the well-being of their patients and they are guided by four ethical principles in pursuing that objective:

- *Beneficence* is the desire for a good outcome and the restoration of health;
- *Non-maleficence* is the avoidance of further harm to the patient;
- *Autonomy* embodies respect for the patient and his or her wishes;
- *Justice* involves reasonableness and equity in decision making.

The conventional medical view is that decisions to withhold or withdraw life sustaining treatment involve an exercise of the physician's clinical and ethical judgment based upon these four principles. Where treatment offers no benefit but serves only to prolong the dying process, it should not be offered.[2] Many physicians are not uncomfortable with this power, viewing it as part of their responsibility to make sound clinical judgements about what treatment options should be offered. The position is summed up in a submission written by a physician. He wrote "the practice of medicine without some concept of what is or is not worthwhile to undertake is neither realistic nor a service to patients" (submission of ICU directors).

Other members of the health care team are also motivated by the ethical principles referred to above in relation to physicians. Although they have less direct responsibility for the ultimate decision making they do have a very close involvement with the daily care of the patient and in the implementation of decisions to withhold or withdraw life sustaining medical treatment. They are also an excellent source of useful knowledge including information about the patient's personal circumstances, expectations and religious or cultural concerns. Consequently, they have an interest in providing relevant information, being heard and being listened to in the decision making process. It is also in the interests of these health care professionals that there be a transparent, authoritative and definitive framework for end of life medical decision making, a clear demarcation of responsibility and a clear understanding of their role in that process. It is additionally in their interests that the decision making protocol has a firm ethical foundation. Members of the health care team who are involved in the implementation of end of life decisions must have a high level of moral comfort in the process so their tasks can be performed with a minimal degree of moral distress, emotional burden or ethical dilemma.

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[1] There is no authoritative definition of who qualifies as a substitute decision maker in Manitoba. Health care providers are forced to operate on the assumption that a close relative may act for a patient who lacks capacity. This is an unsatisfactory state of affairs and we will be releasing a further report recommending legislation stipulating a hierarchy of persons who qualify as substitute decision makers and the principles on which they must base their decisions.

[2] For a discussion of the current by-laws and guidelines of the College of Physicians and Surgeons of Manitoba see, Discussion Paper at pp. 27-29.

Health care institutions seek to support the efficient and ethical delivery of health care services and provide a healing environment for patients. To this extent their interests are similar to those of both physicians and patients. As administrative bodies, however, it is to their advantage to have clear and authoritative guidelines relating to the responsibility for end of life medical decision making and the procedures to be undertaken by the decision maker.

The interest of *patients* is to maximize their autonomous decision making so that they may personally control their end of life passage. This could include not only the right to refuse life sustaining medical treatment but also the right to demand such treatment. Consent of the patient would be essential before such treatment could be withheld or withdrawn. If, on the other hand, the physician is given ultimate authority to withhold or withdraw life sustaining medical treatment the patient's interest is to be heard, to be listened to, to have full and complete information, to have a right to a second opinion and transferral of care to another physician, to have a transparent process for such decision making including appropriate dispute resolution measures and to be assured that there will be accountability of those involved in the decision making process.

The interests of *substitute decision makers* for incapacitated patients often mirror those of the patient. Additionally, they require a clear and authoritative framework to guide them in their decision making or in their participation in the decision making of others and some guidance as to the basis on which they should make decisions for the patient. In particular are they to be guided by the "best interests" of the incompetent patient or are they to reflect the "presumed intent" of the patient?

Family members other than a substitute decision maker have a strong interest in the end of life medical care of their loved ones. This is particularly so when the patient is incompetent and a substitute decision maker is acting for him or her. In this context, family members are not defined solely by the nature of the legal relationship between the patient and the person. "Family members" are those persons who are identified *by the patient or substitute decision maker* as persons who should be consulted in the decision making process. They have an interest in being heard and being listened to and to participate appropriately in the decision making process. There is, for example, no better repository of information about an incompetent patient's intentions, expectations and religious, cultural and personal experience. They also have an interest in a clear, transparent and authoritative decision making framework.

The *public* has a number of interests. The first is a matter of planning. We all face the inevitability of death. Health care directives permit each of us to exercise some control over our health care when we no longer have capacity to do so. It is in the interests of each member of the public to be aware of a clear, transparent and authoritative framework for the withholding or withdrawing of life sustaining medical treatment to prepare and plan for such eventualities. Secondly, the public has an interest in the efficient, ethical and effective use of human and economic resources in the health care system. A right to indefinite, inappropriate health care may be perceived as a mis-allocation of scarce resources.

Members of vulnerable groups include the aged and persons with disabilities. They have special concerns arising from the historic and residual biases in society that the lives of elderly or persons with disabilities are less valuable than those of the young and able-bodied. This generates anxiety when the withdrawal or withholding of life sustaining medical treatment is in the hands of others. That anxiety is enhanced by the use of the concept of "futility" to determine when life sustaining medical treatment may be withheld or withdrawn. As we pointed out in the Discussion Paper,[3] the concept of "futility" risks undue emphasis on qualitative factors and subjective assessments of the value of the patient's life. The interests of these persons will only be fully addressed and their fears completely allayed by a requirement of consent of the patient or the substitute decision maker before withholding or withdrawing life sustaining medical treatment.

Government is in the invidious position of facing seemingly unlimited demands for health care and limited resources to provide it. It expects financial and human resources to be allocated in an ethical, fair and reasonable manner.

There is no simple way in which these diverse interests can be accommodated in a manner that will meet the approval of all. A degree of compromise will be needed to secure a system of rules and procedures which is tolerable to all.

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[3] Discussion Paper at pp. 29-32.

CHAPTER 4

RESPONSES TO THE DISCUSSION PAPER

We have reviewed all the submissions in response to the Discussion Paper. There are among them certain points of agreement and points of disagreement. A brief description of these points of consensus and contention will help to clarify and sharpen the issues involved and assist in finding common ground and solutions.

There was a broad consensus in respect of a number of general propositions. First, there was emphasis on seeking an appropriate *process* for decision making and a commitment to consensus decision making which accommodates the interests of all stakeholders. Second, there was agreement that the decision making process should be informal and sensitive to the particular patient and his or her circumstances. Any more formal process should operate only when consensus decision making fails irretrievably. Third, there was agreement on the need for clear, timely and material information for all interested persons. Fourth, there was a desire for openness and transparency in respect of the rules and procedures for end of life medical decision making. Fifth, there was unanimity that the rules and procedures of determining the withholding or withdrawing of life sustaining medical treatment be uniform across the province and applicable to all health care facilities and physicians.

It is more difficult to detect a consensus on the specific questions we raised in the Discussion Paper. We comment here on some of the more pertinent points. First, there was no agreement on the nature of legal or ethical rules that should govern withholding or withdrawing life sustaining medical treatment. Some favoured legislative rules citing the importance of authoritative, transparent rules that would be applicable uniformly across the province. Others opposed legislation, preferring the use of professional guidelines or a statement of broad policies. Legislative rules were perceived as being too rigid and unable to provide a sufficiently flexible framework to respond to the myriad of individual circumstances that arise for resolution. Some expressed reservations about the extent to which the legislature should micro-manage medical practice and control matters of clinical judgment.

Second, there was a diversity of opinion on the need for the patient's consent to withhold or withdraw life sustaining medical treatment. It ranged from those who view consent as essential in all cases, to those who would temper that policy with various exceptions such as where treatment was not medically feasible, or where the consent of the patient or substitute decision maker was impossible to secure, or where there were insufficient resources to provide treatment or where treatment offended the physician's ethical values; to those who recognize the desirability but not necessity for consent; to those who would not require the consent of the patient where the treatment was medically or ethically inappropriate. Those who favoured the need for consent in all cases did not address whether the correlative duty to provide inappropriate medical treatment indefinitely was acceptable.[1] It is not surprising to find a range of ideas on this most central of issues. There was, however, some strong opinion that more cognizance must be given to patient autonomy in the decision making process.

Third, there were a number of questions which asked the respondents to indicate their preferred approach on the assumption that the patient's consent is *not* an essential requirement to withhold or withdraw life sustaining medical treatment. Some respondents felt that in such circumstances the physician was the appropriate decision maker. In making such decisions, physicians would be guided by the familiar criteria of current medical practice, considerations of the harm and benefit of possible medical treatment options, professional integrity, clinical judgment and the reasonable requests of the patient. Some respondents preferred some sort of independent tribunal to make the decision.

Fourth, respondents disagreed on the issue of dispute resolution if no consensus is reached between the physician and patient or substitute decision maker. Many respondents preferred a step-by-step process moving from an informal process of consensus building to more formal dispute resolution. The possible steps included the initial discussion between those who were immediately concerned such as the patient or substitute decision maker and health care professionals. The next step might include other persons such as ethicists, pastoral care professionals or social workers who could assist in finding a solution acceptable to all. The patient might then seek a second medical opinion or a transfer of care to another physician. Continuing disagreement might then require a somewhat more formal step such as mediation. Beyond that there may be resort to an independent tribunal or the courts to resolve the matter. There was, however, a clear preference for a preventive approach which would maximize the chance for agreement and minimize the need for more formal mechanisms.

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[1] The question in the Discussion Paper was "Should health care providers be *required* to obtain a patient's consent before withholding or withdrawing treatment? " (emphasis added).This question appears to have been interpreted by some respondents as should the health care providers *try* to secure the consent of the patient. The response almost uniformly was "yes". This interpretation is evidenced by the fact that many respondents who answered the question in the positive qualified that response in answers to later questions. If the question read "Should the health care provider be required *in all cases* to obtain a patient's consent before withholding or withdrawing treatment?" the answers might have changed.

CHAPTER 5

PRINCIPLES AND POLICIES

The Commission believes that there are certain fundamental principles and policies that should be reflected in the rules or framework controlling the withholding or withdrawal of life sustaining medical treatment.

1. There must be a uniform approach and process to withholding or withdrawing life sustaining medical treatment across the province and in all health care institutions. The manner in which these decisions are made should not depend upon which health care institution one is admitted to. Fairness and equity demand equal process.

2. The uniform approach must apply to all decisions to withhold or withdraw life sustaining medical treatment whether in the form of Do-Not-Resuscitate (DNR) orders or other decisions.

3. There must be a uniform approach which treats all citizens fairly and equitably and provides equal access to medically appropriate medical care to all without bias or favour. In particular, equal treatment must extend to the elderly and persons with disabilities. Neither of those circumstances is a sign of terminal illness or impending death.

4. The decision making process must be clear and transparent and must be communicated clearly not only to the patient and his or her family but also to the public in order to facilitate a broad understanding of how these decisions are made. A transparent system will facilitate personal planning for the future and promote trust in the health care system.

5. Emphasis must be placed on the *process* for decision making rather than the formulation of specific rules which would purport to dictate the decision. The process must be designed to facilitate an *agreement* between the physician and the patient or his or her substitute decision maker. It should have the following features:

    - the process should be instigated by the attending physician;
    - the process should begin at the earliest appropriate time to provide an opportunity for considered and informed discussion and decision making;
    - full and complete information must be provided by the attending physician to the patient/substitute decision maker about the nature of the patient's condition, prognosis, treatment options (including those that the physician may not favour) and the expected benefit or harm of those options;
    - a full and complete explanation by the attending physician why he or she believes that withholding or withdrawal of life sustaining medical treatment is medically

appropriate;

- a full and complete discussion between the attending physician and the patient of his or her personal, cultural circumstances and spiritual beliefs and concerns insofar as they are relevant to the decision at hand and welcomed by the patient;
- a full and complete discussion between the attending physician and the patient of his or her wishes, concerns, expectations and preferred treatment options including consideration of a time limited trial of therapy;
- a full consultation with the family of the patient[1] unless such communication is prevented for some documented reason such as impracticality, breach of privacy or confidence;
- full information and assurances to the patient that a withdrawing or withholding of life sustaining medical treatment does not amount to an abandonment of care and compassion and that palliative treatment will be provided.

Direct communication between the attending physician and the patient or the substitute decision maker is an essential feature of this consensus building process. In other than exceptional circumstances, such as impossibility, the obligations of the physician outlined above are personal and must not be delegated to other members of the health care team.

6. Where a consensus cannot be reached between the physician and the patient or substitute decision maker about withholding or withdrawing life sustaining medical treatment resort should be had to other available informal dispute resolution procedures. Institutional facilitators and mediators such as ethicists, pastoral care workers and other qualified persons can assist in finding a consensus between the physician and the patient/substitute decision maker. In some circumstances, independent external mediators may be helpful. Every reasonable effort should be used to secure agreement in as informal and sensitive a process as possible.

7. Where there is disagreement between the physician and the patient or substitute decision maker on the appropriate course of action, the patient must be given an opportunity to secure an independent second opinion from a physician who is not a member of the patient's health care team and/or request that his or her care be transferred to another physician.

8. Where all preceding measures have failed to produce an agreement the physician may, after an appropriate notice period, withhold or withdraw life sustaining medical treatment where such treatment would be medically inappropriate or professionally unethical. The notion of futility should not be used because of the pejorative connotation of that word and the fact that it risks undue emphasis being placed on an evaluation of the life at issue. Such subjective views may not be entirely extinguishable from the determination of whether

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[1] We reiterate here that "family" in this context includes all those whom the patient or substitute decision maker identifies as persons who should be consulted in the decision making process.

treatment should be withheld or withdrawn, but to the extent possible the decision should be ultimately justifiable on the basis of a physician's professional and ethical obligations and clinical judgment after the full process that we contemplate has taken place.

9. A corollary of the foregoing is that we do not favour a right to indefinite life sustaining medical treatment. The appeal of autonomous decision making and personal control of all end of life medical decision making is initially attractive. An unfettered right to life sustaining treatment, however, may result in unreasonable demands being made for indefinite inappropriate medical treatment. We cannot judge how significant a risk this is and we cannot quantify the burden on the health care system but there are additional and independent reasons for caution. First, the recognition of such a right may be inconsistent with the fundamental professional and ethical obligations of physicians not to provide medically inappropriate treatment. Second, it opens the door to a more general right to other forms of inappropriate medical treatment prior to the end of life situation. Third, human and economic health care resources are strained and some professional control over the use of medical technology to sustain life *indefinitely* is appropriate.

10. We do not favour the establishment of internal or external committees, boards or arbitrators to hear appeals where the process outlined above has failed. It is anticipated that such cases will be infrequent and the delay, cost and formality involved in administrative tribunals is unattractive. The logistics of such an option are complicated by the number and scattered geographic location of provincial health care institutions and the financial and human resources involved. There is also the unsettling prospect of creating a disincentive to resolve these issues informally with good faith and goodwill. Final resort to the courts will remain available where the procedures designed to achieve consensus have irretrievably broken down.

CHAPTER 6

THE *PROPOSED "SAMPLE"* POLICY OF THE COLLEGE OF PHYSICIANS AND SURGEONS OF MANITOBA

The College of Physicians and Surgeons of Manitoba has recently spent a great deal of time and energy on the issue of end of life medical decision making. It forwarded to us a copy of their *Proposed Policy on Withholding and/or Withdrawing Life-sustaining Treatment* (which is attached as Appendix C and which is referred to below as "the Policy"). We have found this document to be of considerable assistance in our deliberations on these issues. It is not a panacea. It addresses only the obligations of physicians in the end of life medical decision making process. Furthermore, the College is influenced in both the resolution of these issues and in the drafting of the Policy by the fact that a breach of the defined obligations may result in disciplinary proceedings being brought against a physician. Nevertheless, we are attracted by the College's formulation of a consensus building process which reflects, in many respects, the principles that we favour. The Policy contains a clear formulation of a transparent process which recognizes the competing interests at stake and maximizes the opportunity for an informed consensus between the physician and the patient or his or her substitute consent giver. The Policy has a further advantage. It reflects the tentative views of the governing body of Manitoba physicians and it can, therefore, be relied upon as a realistic and pragmatic framework for end of life medical decision making that is compatible with the realities of current medical practice.

We do not fully endorse the Policy in all respects but it is a very useful general framework for analysis and constructive criticism. Consequently, we set out below the full wording of the Policy and, at appropriate points, we have interjected our comments and criticisms.

SAMPLE POLICY
WITHHOLDING AND/OR WITHDRAWING LIFE-SUSTAINING TREATMENT

Background

> The relationship between physician and patient is based on the ethical principles of justice, beneficence, non-maleficence and respect for patient autonomy. The primary goal of medical treatment is to restore or maintain patient health as much as possible, maximizing benefit and minimizing harm.

In our Discussion Paper, we defined patient as including a substitute decision maker. The Policy distinguishes between the terms "patient" and "substitute decision maker" on the grounds that their interests and views are not always identical. We recognize the validity of that point.

> Patients, their families, substitute decision makers and health care providers require a supportive environment in which to address issues relating to end of life care. The term family as it is used throughout this Policy includes those who are closely linked to a patient in knowledge, care and affection and may include not only biological family and those linked to a patient by marriage, but may also include a patient's family by choice.

We strongly endorse the first sentence and agree with the wide definition of "family" described herein. We would prefer, however, a clearer recognition that the scope of the "family" is ultimately determined by *the patient or substitute decision maker* as persons who should be consulted in the decision making process.

> Physicians have a responsibility to consult with their patients or substitute decision makers, and **where appropriate**, their patients' families, regarding either withholding or withdrawing life-sustaining treatment and to attempt to facilitate a consensus on how to proceed. Approaches towards reaching a consensus and/or managing conflict need to be tailored to the particular concerns and circumstances of each patient and will require physicians to use their best clinical and ethical judgment. Physicians should recognize that decisions concerning life-sustaining treatment may need to be revisited as patient circumstances change.

Reference is made in a number of passages in the Policy to the obligation of the physician to consult with family members *"where appropriate"*. We are concerned about the uncertainty embodied in that term and the degree of uncontrolled discretion that it entrusts to physicians. We recognize that there has to be some discretion in this matter but we prefer wording such as "where possible" which would require a physician to provide some reasonable justification for failing to consult with "the family". Justification might include impossibility such as when the family members are not available, impracticability such as time constraints, and confidentiality concerns such as directions from the patient that one or more family members should not be consulted. We have highlighted in bold other points of the Policy where the words "where appropriate" are used in this context.

> This Policy sets out a process-based approach to making these decisions and sets the parameters within which these decisions should be made. It focuses on conflict resolution when life-sustaining treatment is sought and a physician believes that it is ***medically inappropriate*** for the patient.

We noted in our Discussion Paper[2] that the term "futile" has conventionally been used to describe medical treatment which is useless or ineffective and consequently may be withheld or withdrawn. We drew attention to two aspects of the word futile. Physiological futility describes a treatment that will not work or one which cannot achieve its desired goal. It is largely a matter of clinical medical judgment. Qualitative futility introduces the highly controversial concept of treatment which is not worth doing or one that will not produce a desirable outcome. The word futile tends to emphasize the qualitative connotation of the word and suggests that a predominantly value laden judgment is being made. This has led to the term falling into disrepute. In particular, it generates discomfort in vulnerable groups such as persons with disabilities and the elderly. We recognize that end of life decision making can never be a purely clinical issue and that subjective values inevitably intrude to some extent. Nevertheless, terminology is important and we agree with the deliberate decision of the College to abandon use of the word futile in its protocol and replace it with the term "medically inappropriate". We have highlighted the consistent use of the term above and below in bold italics. In our view, this term is preferable because it emphasizes the clinical aspects of the decision making and focuses on the nature of the terminal illness, the degree of benefit that may be achieved, the harm and suffering consequent on treatment and the ethical and professional obligations of physicians.

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[2] Discussion Paper at pp. 29-39.

> The approach recognizes:
>
> 1. the right of patients or substitute decision makers and, **where appropriate**, patients' families to participate in decisions regarding life-sustaining treatment; and
> 2. physicians' integrity and autonomy by providing a basis for physicians to refuse to provide life-sustaining treatment when they determine that it would be ***medically inappropriate*** to do so.
>
> The spectrum of clinical scenarios raising consideration of withholding and/or withdrawing life-sustaining treatment ranges from abstract discussions about potential end of life circumstances to unforeseen medical emergencies. There will be varying degrees of possible patient or substitute decision maker participation and/or the involvement of families across the spectrum; however, the principles outlined herein apply to all decisions to withdraw or withhold life-sustaining treatment. While the manner in which the requirements will be met may vary as necessary to accommodate unique circumstances, the process followed must adhere to the requirements as closely as possible in each case.

We strongly support the notion that the Policy apply to all decisions to withhold or withdraw life sustaining medical treatment. We noted in our Discussion Paper[3] that there was an uneven practice in Manitoba in respect of this kind of decision making in general and in the making of DNR orders in particular. A sense of fundamental fairness is promoted by the consistent application of protocol to all end of life decision making. *In particular this Policy will terminate any continuation or implementation of any form of automatic DNR assignations.*

> **Scope**
>
> This Policy applies to all physicians.

This, too, promotes uniformity across the province and among institutions.

> **Policy**
>
> **A. The *Most Responsible Physician***
>
> The identity of "*most responsible physician*" must be clearly communicated to all members of the health care team, the patient or substitute decision maker and, **where appropriate**, the patient's

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[3] Discussion Paper at pp. 39-40.

family, and must be documented in the patient's medical record.

We have some concerns about the uncertainty in the phrase "health care team". It appears in a number of places in the Policy and is identified by us by underlining. This may be construed quite narrowly as including only the attending physician, attending specialists and nurses or it may extend to other medical (nurses aids, technicians) or non-medical (social workers, ethicists) personnel. We would favour a clear definition of the term and would also favour a wide definition to include all of those who have been involved in the care of the patient.

> The *most responsible physician*:
>
> 1. is the coordinator of the patient's clinical care;
> 2. is the person to whom the patient or substitute decision maker and/or family members and other health care providers look for direction and dialogue;
> 3. serves as a consistent clinical presence, even when consultants or other health care providers may be variably involved; and
> 4. is not necessarily the clinician with the most expertise, but rather the one with the most meaningful ongoing relationship with the patient, by virtue of history, circumstance, relationship, or request.
>
> For a patient admitted to a health care facility such as a hospital or personal care home, it is the responsibility of the physician identified on the chart addressograph or database to either act as the *most responsible physician*, or to clearly designate another willing physician as the *most responsible physician*. For a patient in an emergency department or intensive care unit, the *most responsible physician* may be the emergency room physician or intensive care physician in urgent situations, but may often be the family physician or a specialist who has assumed care of the patient. Ultimately, it is the responsibility of the emergency department or intensive care unit staff to be aware of the identity of the *most responsible physician* for a given patient under their care. For patients in the community, the *most responsible physician* is either the patient's family physician, or the specialist who has taken primary responsibility for ongoing medical care due to the complexity of the case.
>
> When a physician is confronted with a clinical scenario in which withholding or withdrawing a life-sustaining medical intervention may be ***appropriate***, where that physician is not the patient's *most responsible physician*, the physician should consult with the *most responsible physician*, if possible. Otherwise, that physician should assume the role of the *most responsible physician* or find someone who will.

We strongly support the notion of "the most responsible physician". It is very advantageous to patients, substitute decision makers and family members to know that there is a single identified physician who has overall responsibility for the care, provision of information, advice and assistance. In an acute care hospital, a patient may be attended to by a large number of health care professionals with defined and limited tasks and responsibilities. Moreover, some of those professionals change from shift to shift and from day to day. It may be difficult for the patient and his or her family to determine who ultimately is in charge. This problem is exacerbated for substitute decision makers and family members who are only able to visit from time to time and not at the same time during the day. These obstacles to communication, information and advice complicate the situation unnecessarily and exacerbate the emotional toll of end of life medical decision making. The success of a consensus seeking process is enhanced by this concept of a single responsible physician with whom the patient, substitute decision maker and family can fully and consistently engage.

> ### B. Prognosis and Treatment Options
>
> The most responsible physician, in consultation with other members of the health care team, should consider the range of ***medically appropriate*** treatments for the patient, including those that are life-sustaining interventions that may be withheld or withdrawn. In assessing the patient's prognosis and the treatment options, the *most responsible physician* must rely on the best available clinical evidence, including, **where appropriate**, consultation with a specialist.
>
> Where the *most responsible physician* is uncertain and/or is ambivalent about any aspect of the range of ***medically appropriate*** life-sustaining treatment for the patient, prior to reaching a conclusion as to what form of treatment is most ***medically appropriate*** for the patient, the *most responsible physician* must seek additional clinical input:
>
> 1. where possible, from other health care team members, such as another physician involved in the patient's care, and/or
> 2. by consulting with at least one other physician, preferably inside the same institution, or if not available;
> 3. by consulting with a physician outside the institution by telephone.

The preceding paragraphs emphasize that the determination of what is medically appropriate treatment is primarily a professional, clinical decision based on an assessment of the patient's condition, the clinical evidence and professional consultation. As we noted earlier some qualitative analysis is unavoidable but the emphasis, in our opinion, is in the right place.

> ### C. Consultation with the Patient or Substitute Decision Maker and/or Family
>
> **Patient**
>
> Where the range of ***medically appropriate*** treatments involve the possibility of withholding or withdrawing life-sustaining treatment, the *most responsible physician* must, as early as possible and where possible, while the patient is competent and capable of participating in the discussion, consult with the patient regarding the patient's prognosis and wishes for treatment. In the case of many chronic diseases likely to result in eventual deterioration of health and death, timing of initiation and the extent of such discussions will depend on many factors, including the personal circumstances of the patient, and will involve the exercise of clinical judgment by the physician.

This paragraph contains an appropriate recognition of the importance of patient autonomy and the need for the participation of the patient at the earliest appropriate time in the decision making process.

> **Substitute Decision Maker**
>
> Where the patient is not competent to make decisions regarding care, the *most responsible physician* must, as early as possible and in consultation with others **where appropriate**, identify the patient's substitute decision maker.
>
> If the patient has a health care directive appointing a health care proxy, the *most responsible physician* must accept the appointment as expressed in the directive. Where the directive identifies a health care proxy, the proxy will be the patient's substitute decision maker.

> Where there is no health care directive and/or proxy, the *most responsible physician* must ascertain the identity of the person with legal authority to make decisions on behalf of the patient and that person will be the patient's substitute decision maker. Depending on the circumstances, the substitute decision maker may be a family member, legal guardian, court appointed committee or other party such as the Public Trustee. The physician must consult with the substitute decision maker in the same way as the physician would otherwise consult with the patient.

We note that the College was unable to provide a clearer definition of who is the substitute decision maker because of the state of the law in Manitoba. There is neither a common law definition of a substitute decision maker nor any applicable legislation. There is also no authoritative statement of the principles on which the substitute decision maker must base his or her decision. There is a choice between following the "presumed will of the patient" and "in the patient's best interests". This is a significant problem in respect of all medical care where the patient is temporarily or permanently incompetent. Health care professionals and health care institutions must operate on the belief that decision making by a close relative who acts in the best interests of the incompetent patient will receive judicial recognition and approval. We regard this state of affairs as unsatisfactory and, as we noted earlier, we will, in a further report, make recommendations for legislation stipulating a hierarchy of persons who qualify as substitute decision makers and the principles on which their decisions should be based.

> **Consultations**
> In consultation with the patient or the substitute decision maker, the *most responsible physician* must attempt to reach a consensus on how to proceed. The consultations with the patient and/or substitute decision maker should include:
>
> - with the assistance of patient or substitute decision maker, identification of others who should be involved in the discussion, and, where possible, accommodating the participation of anyone identified in the discussion;

We note with approval the wide consultation anticipated by this provision extending to all those identified by the patient or substitute decision maker and limited by possibility not by the term *"where appropriate"* used elsewhere in the Policy in similar circumstances.

> - an inquiry as to the patient's personal, cultural and family issues that may impact on the decision, such as their existing knowledge, awareness and understanding of the patient's condition and treatment options and their interest in pursuing treatment options;

We recommend that "spiritual" or "religious" be added to the issues listed for consideration and note some lack of clarity or consistency between the issues listed and the examples given.

> - a description of the nature of the underlying condition or ailment;
> - the options for treatment and their expected outcome;
> - the prognosis with or without medical intervention in the form of life-sustaining treatment;
> - the reason why the physician feels that initiating or continuing life-sustaining treatment may be ***medically inappropriate***;
> - options including palliative care and hospice care where applicable;
> - assurances that the patient will not be abandoned in the event that medical intervention is either withheld or withdrawn;

- confirmation that other forms of medical treatment such as palliative care measures which emphasize patient comfort and dignity will be provided;

We agree with this list of factors to be discussed with the patient or the substitute decision maker. The listing of factors should not disguise the importance of sensitivity and compassion in this consensus building process and the need to address fully the patient's desires and the importance of meeting those concerns where it is medically appropriate to do so. While the former may be implied the latter might be in need of further emphasis. We would, therefore, suggest a further factor:

- an exploration of the patient's needs, desires, and expectations including his or her personal choice of treatment and the reasons for that choice.

This may give more prominence to the patient's interests in autonomy and personal decision making.

We note our strong agreement with the last three factors relating to palliative care. They are critical components of a compassionate policy.

- where the *most responsible physician* recommends either withholding or withdrawing life-sustaining treatment and the recommendation is not accepted, an exploration of the reasons why the patient or substitute decision maker wishes treatment to be continued and address these issues directly with a view to resolving them, including, **where appropriate**:
  1. a description of the decision making process, including the information that the physician has the responsibility to recommend and provide only those treatments that the physician determines are ***medically appropriate*** for the patient;
  2. exploring feelings of guilt that may exist and addressing fears that those involved in the decision are causing the patient's death by agreeing with a recommendation that life-sustaining treatment be withheld or withdrawn;
  3. among the solutions offered, offering a time-limited trial of therapy with clear predefined outcome goals to accommodate either medical issues or satisfy personal concerns of patient, substitute decision maker, the patient's family or others;
  4. mutually agreeing to take any additional or alternative steps to facilitate a consensus including, but not limited to, involving institutional resources such as a patient advocate, mediator, ethics committee or institutional review process;
  5. an offer of institutional resources such as social work, chaplaincy, or bioethics to assist the patient or substitute decision maker or family with their psychosocial, cultural, spiritual, and informational needs;

The listing of possible dispute resolution techniques listed 1-5 is weakened by the introductory words that these steps may be taken *where appropriate*. We would prefer stronger language obliging these steps be taken unless a failure to do so could be justified on some grounds such as a failure of the patient or substitute decision maker to cooperate, impossibility, time constraints, etc. This would more vigorously implement our view that all reasonable steps be taken to secure a consensus. Points 1-3 would seem to be compatible and consistent with the existing ethical and professional obligations of physicians and could comfortably be required of them. We agree that the dispute resolution process should be one which promotes and facilitates agreement or consensus between the patient/substitute decision maker and the most responsible physician. We do not favour an arbitration process or other mechanism that would place the ultimate decision making authority in a third party.

It may not , however, be appropriate for the most responsible physician to carry the burden of implementing the dispute resolution process contemplated in steps 4 and 5. A sharing of initiative and responsibility is more appropriate. The most responsible physician might be required to outline the mediation and conciliation processes that are available and indicate a willingness to participate in them. This may comfortably be regarded as an obligation of the physician and this should not require his or her consent as indicated by the language of the Policy. The patient or substitute decision maker will then decide whether or not they wish to pursue one of the available options. The health care institution should then assume responsibility for facilitating funding and implementing the chosen dispute resolution method. The latter responsibility would require the cooperation of the health care institutions. They are not subject to the control of the College.

There is also, in our view, insufficient emphasis on the use of third party mediators, conciliators and/or facilitators who are not part of the medical bureaucracy. Institutional facilitators and mediators may be perceived as being too closely identified with the interests of the physician and the health care establishment. We recognize, however, that the use of third party facilitators or mediators would also require the financial and logistical support of thc health care institutions.

We are reluctant to suggest a more detailed and definitive dispute resolution process for fear that it would not be appropriate for every health care institution. We, however, wish to leave no doubt that cooperatively the most responsible physician and the health care institution should be willing to pursue and facilitate all reasonable mediation and conciliation measures that the patient or the substitute decision maker desires.

We recognize that there are obstacles to the use of mediation where the patient is not in a health care institution. When the patient receiving or requesting life sustaining measures is at home, more reliance must be placed on the patient's physician to suggest steps that are practical and appropriate to the circumstances encountered. The physician may suggest the assistance of the patient's religious adviser or a close family friend to facilitate discussion and consensus. We cannot foresee every circumstance but home care must not be an excuse to avoid the implementation of the Policy to the full extent possible in the circumstances.

> - documentation of the pertinent details of this communication in the patient's health record.
>
> If a consensus results from the consultation with either the patient or the substitute decision maker, the decision can be implemented without the consent of the patient's family or others, but if a medical intervention is to be withheld or withdrawn, the *most responsible physician* should, with the consent of the patient or substitute decision maker, attempt to communicate with the family members and fully explain the reasons for the decision.

We agree with the conditional obligation on the most responsible physician to inform the family of the decision to withdraw or withhold life sustaining medical treatment. We note that it is not qualified by the words "*where appropriate*".

D. Additional Clinical Input

> If consensus cannot be reached as a result of the consultations referred to above, the *most responsible physician* must address with the patient or substitute decision maker the option of the patient or substitute decision maker's obtaining an independent medical opinion concerning the medical appropriateness of the intervention in question and facilitating a request for an independent medical opinion by providing all relevant medical information to the consultant chosen by the patient or substitute decision maker.

We agree that the patient should have a right to an independent second opinion. We detect some ambiguity in the language of this paragraph created by the first clause. It may be interpreted as requiring that every option for agreement such as using all institutional and third party mediation resources must be exhausted before a second opinion can be sought. This is probably not the intent of the draftsperson. The intent was likely to allow a second opinion to be sought whenever disagreement becomes apparent. That intent can be clarified by excision of the words "as a result of the consultations referred to above" from the first line. We are also concerned about the feasibility of a patient or substitute decision maker exercising this option. A patient or substitute decision maker may not have the knowledge or ability to identify and seek out another physician for an independent second opinion. It is arguably inappropriate to require the most responsible physician to provide names or be actively involved in securing the second opinion. This would entail a physician taking the time to find a colleague who may not agree with him or her. The most appropriate source of assistance and advice would appear to be the patient advocates and advisers in the health care institutions. Their active role in advising and facilitating the second opinion option is crucial in making sure that it is a meaningful one.

The physician and other health care providers must play a more active role when the patient is receiving home care and cannot take advantage of the institutional supports. The physician may, for example, provide useful information such as the availability of the Directory of Physicians on the website of the College of Physicians and Surgeons of Manitoba[4] or suggest the names of individual specialists for a second opinion.

E. The *Most Responsible Physician*'s Onus to Decide

> **Where the patient is not competent and it is not reasonably possible to consult with the substitute decision maker, the onus is on the *most responsible physician* to decide whether or not life-sustaining treatment should be withheld or withdrawn. When a physician is confronted with making such a decision without the input of the patient or someone to whom the authority to represent the interests of the patient has been delegated, the onus is on the *most responsible physician* to make the decision based on his/her determination of what is in the best interests of the**

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[4] <http://www.umanitoba.ca/colleges/cps> (date accessed: 2 December 2003).

> patient. In such circumstances, the *most responsible physician* should consider consulting with other members of the health care team, including another physician in reaching a decision. The *most responsible physician* should communicate the decision to other members of the health care team as soon as possible after the decision has been made.

We do not agree with the wording of the penultimate sentence of this paragraph. We prefer much stronger language which would require the most responsible physician to consult with the other members of the health care team (construed broadly as recommended above) and another physician. This can be achieved by removing the words "should consider consulting" and replacing them with "shall consult where possible".

F. Transfer of Care

> The *most responsible physician* must, where possible, provide the patient or substitute decision maker with an opportunity to identify another physician willing to assume care of the patient and facilitate the transfer at any time when the patient or substitute decision maker requests that the patient's care be transferred to another physician who is willing to assume care of the patient.

We agree with this option to transfer care to another physician. In some circumstances, however, the right to transfer of care may, in practice, be illusory. This paragraph requires the patient (or substitute decision maker) to *identify* another physician who is willing to assume care. A terminally ill patient may not have the energy, information or sophistication to exercise this right. The substitute decision maker may lack knowledge and sophistication. The patient or substitute decision maker needs the assistance of someone with knowledge of the health care system. It would seem inappropriate to require the most responsible physician to effect the transfer of a dissatisfied patient. Consequently the responsibility for information and assistance in facilitating a transfer of care should be assigned to the appropriate personnel of the health care institution. If assistance is not provided the right to a transfer of care may be illusory.

Many patients who are seeking a transfer of care will be in a health care institution and will have access to information and assistance. We do recognize, however, that some will be receiving home care and will not have access to the services provided by an institution. In those circumstances, more will be required of the patient's physician and other home health care providers. Patients may, for example, be referred to the Directory of Physicians available on the College of Physicians and Surgeons of Manitoba's website[5] or given a print out of that list which provides the names, addresses and specialty of all physicians.

G. Impasse- Notice of Decision

> If, despite all reasonable efforts, a consensus cannot be reached, the *most responsible physician* must, where possible, provide at least 72 hours notice to the patient or substitute decision maker, preferably in writing, prior to withholding or withdrawing life-sustaining treatment.

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[5] <http://www.umanitoba.ca/colleges/cps> (date accessed: 2 December 2003).

We recommend that the notice period be extended from 72 hours to seven days. There is no pressing need for efficiency and haste at this pivotal and critical moment. There must be ample time not only to absorb intellectually and emotionally the information that is being delivered, but also to seek a transfer of care, to receive advice and counselling or to commence legal proceedings. In particular, the 72 hour notice period may well be too short a time to commence legal proceedings, particularly where notice is given on a Friday.

We also prefer stronger language in respect of the need for the notice to be in writing. This should not merely be a preference but a requirement. It is important that there be clear and reliable evidence of the intentions of the most responsible physician. This is an aspect of the need for full documentation which we discuss further below.

H. Withholding or Withdrawal of Life-sustaining Treatment

> The *most responsible physician* may withhold or withdraw life-sustaining treatment, or authorize other members of the health care team to withhold or withdraw life-sustaining treatment, including intensive care:
>
> 1. with the consent of the patient or substitute decision maker at any time;
> 2. without the consent of the patient or substitute decision maker:
>   - i) where the *most responsible physician* has otherwise complied with all of the requirements of this policy **and**
>   - a) the *most responsible physician* believes that it is medically appropriate for the patient, **and**
>   - b) the *most responsible physician* is unable to obtain consent because the patient is not competent, **and**
>   - c) it is not possible to consult with the substitute decision maker;
>
>   **OR**
>   - ii) where consultation with the patient or substitute decision maker has not resulted in consensus:
>   - a) **after** the notice period has elapsed, **and**
>   - b) in the absence of a transfer of the patient's care to another physician **or** the initiation of legal steps to prevent the treatment from being withdrawn or withheld at any time during the notice period.

We recommend that the wording of 2 ii) be changed to make express that which might otherwise need to be implied. We suggest the following wording:

- ii) where the most responsible physician has otherwise complied with all the requirements of this policy **and**
    - a) where consultation with the patient or substitute decision maker has not resulted in a consensus, **and**
    - b) the most responsible physician believes that it is medically appropriate for the patient, **and**
    - c) after the notice period has elapsed, **and**
    - d) in the absence of a transfer of the patient's care to another physician **or** the initiation of legal steps to prevent the treatment from being withdrawn or

> withheld at any time during the notice period.

This is such a critical passage that the language should be as clear and as unambiguous as possible.

SOME ADDITIONAL COMMENTARY ON THE SAMPLE POLICY

The great majority of the suggestions and comments made above on the Policy has been motivated by a desire to achieve greater clarity and to give more emphasis to the patient's interest in autonomy and personal decision making. Nevertheless, as we noted earlier we strongly favour the general thrust of the College's sample Policy and the consensus building approach it embodies. We also accept that, subject to the Policy (with the amendments we suggest), the most responsible physician may withhold or withdraw *medically inappropriate* life sustaining treatment. There are, however, two additional and overriding concerns identified in many of the submissions made to the Commission which must be addressed. They are *transparency* and *accountability*. They require separate discussion.

Transparency of end of life medical decision making requires not merely that there is a fair and defensible policy in place. It demands that the operative policy be known not only to the patient and the substitute decision maker but also to the general public who may wish to plan their affairs for future eventualities. The policies and by-laws of professional associations such as the College may not be easily available to all members of the public.[6] In our view, operative policies on end of life medical decision making should be communicated widely and written copies should be available in physicians offices, health care institutions and on appropriate websites. We recommend the widest possible publicity be given to the manner in which these decisions are made. This may require some cooperation between the College of Physicians and Surgeons of Manitoba, the regional health authorities, Manitoba Health and health care institutions. We view this publicity/educational function as critically important to allay unfounded suspicions about the end of life medical decision making process and foster public confidence in it.

The danger in any consensus seeking process is that lip service will be paid to it and full implementation of its spirit and intent will be undermined by those physicians who continue to favour unilateral paternalistic decision making. There must, therefore, be *accountability* for the failure to implement the policy. This can be achieved in a number of ways.

First, the extensive publicity and public education of the end of life decision making policy that we contemplate will guard against the risk of non-compliance. Secondly, accountability is enhanced by a full and complete documentation of the decision making process. Reference is made to the need for documentation in the Consultation section of the sample Policy. We would recommend that it receive more emphasis. In our view, it is vital that there be a full and complete documentation by the most responsible physician of all the individual steps contemplated by the Policy and a reliable record of the step-by-step evolution of the full decision making process. A clear stipulation in the Policy of such an obligation would underscore the importance of full compliance with the process and help to ensure that the appropriate steps have been carried out. Thirdly, the degree of accountability depends upon the final form in which the policy is implemented by the College. The Policy may be implemented as a by-law, a statement or a guideline. By-laws set out required conduct of physicians. Statements describe conduct that physicians are expected to follow. Guidelines indicate recommended practice. Disciplinary proceedings on the grounds of unprofessional conduct are more likely to be brought where there has been an alleged breach of a by-law or a statement. We recommend that the Policy, with the amendments that we suggest, be embodied in a by-law of the College, where, indeed the current regulations are found. At the very least, it should be embodied in the statement of the College. This will facilitate accountability and act as a deterrent against failure to comply with the Policy.

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[6] The by-laws, statements and guidelines of the College of Physicians and Surgeons of Manitoba are available on the College's website at: <http://www.umanitoba.ca/colleges/cps> (date accessed: 2 December 2003).

CHAPTER 7

THE CONTRIBUTION OF OTHER HEALTH CARE BODIES AND INSTITUTIONS

We believe that the sample Policy of the College of Physicians and Surgeons of Manitoba with the adjustments and amendments that we suggest will provide an appropriate framework for end of life medical decision making. All end of life medical decisions involve one or more of the province's physicians and it is, therefore, appropriate that the controlling principles are formulated by the body which is legislatively mandated to regulate the profession in the public interest. While we do not agree with every word of the Policy, we recognize the commitment to consensus decision making, the desire to balance competing interests fairly, the determination to protect the public interest without creating undue obstacles to the ethical practice of medicine and the willingness to foster a participatory relationship of mutual trust and goodwill between the physician and the patient. The sample Policy is not, however, a complete answer to these difficult issues. We have indicated ways in which it may be improved to provide more clarity and greater protection of the patient's interests.

Furthermore, we recognize that there are other bodies involved in the delivery of health care which play a significant role in addressing and facilitating the end of life decision making process. Institutions, such as regional health authorities and health care institutions, have been developing policies and protocols which are similar to but not identical to those favoured in the College's sample Policy. We provide, by way of example, the recent initiative of the Winnipeg Regional Health Authority's *Principles Related to End of Life Decisions* approved by its Board of Directors in June 25, 2002,[1] which is reproduced below with commentary. This is complemented by the WRHA's draft *Advanced Care Planning* initiative[2] which facilitates end of life decision making and provides a framework for its written documentation. An important objective of this initiative is to achieve a degree of cohesion and consistency among health care institutions within the jurisdiction of the WRHA.

PRINCIPLES RELATED TO END OF LIFE DECISIONS

The following principles should guide clinical practice at all WRHA sites that deal with end of life issues and decisions, where time permits. These principles should guide policy development regionally and within facilities.

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[1] Letter from Winnipeg Regional Health Authority, Submission to the Manitoba Law Reform Commission on Discussion Paper: Withholding or Withdrawing Life Sustaining Treatment, Exhibit "A" (December 19, 2002).

[2] Id., Exhibit "B". In its covering letter, the WRHA states that this initiative has not yet been finalized but is attached for informational purposes. We have attached it to our Report as Appendix D.

PRINCIPLES:

1) Health care providers recognize and value the need for patients or their legal representative, and their families (where appropriate) to be fully informed of the potential benefits and risks associated with different treatment options. A legal representative is someone who would be recognized by the courts as being able to act on behalf of an incompetent patient. (For example, a proxy under The Health Care Directives Act, or a Committee entitled to make personal care decisions, or the parents of a minor child.)

This provision recognizes the legal and ethical obligation of health care providers to secure informed consent to medical treatment and mirrors the College's sample Policy. The term "substitute decision maker" used by the College is preferable to that of "legal representative". The term "health care provider" is not defined in the policy. This is of significance because some of the obligations outlined in this principle are imposed on health care providers and some are assigned exclusively to physicians. We assume that the terms have been used deliberately to allocate the various responsibilities. It is, therefore, useful to have a clear definition of "*health care provider*".

2) Health care providers recognize the rights of patients, or their representatives, to participate in all treatment decisions.

This provision protects a right of participation in decision making implying that the final decision is that of the physician. The issue of family participation is not dealt with.

3) Health care providers accept that limits may be provided by "health care directives" on the nature of treatments that they may administer, in accordance with the applicable legislation.

This provision mirrors the established legal right to refuse medical treatment under *The Health Care Directives Act*.[3]

4) Physicians have an obligation to refuse to order requested treatments that are not consistent with appropriate standards of care.

This provision confirms the physician's power to withhold or withdraw life sustaining medical treatment. The loaded concept of "futility" is not used but the terminology is inconsistent with that of the College's phrase "medically inappropriate". The concept of "the most responsible physician" as used by the College would more clearly define who has the ultimate responsibility to make the decision.

5) Physicians shall ensure, with other health care providers, that "advance care planning" with patients and appropriate others is discussed and documented. This is a means to operationalize "health care directives" where they exist, or to plan for end of life issues where they do not exist.

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[3] *The Health Care Directives Act*, C.C.S.M. c. H27.

The clarity of this provision would also be improved if the concept of "the most responsible physician" developed by the College was used rather than "physicians . . . with other health care providers". Also, no guidance is given as to the meaning of "appropriate others".

> 6) All "advance care plans", including any orders restricting treatment such as "Do Not Attempt Resuscitation" (DNAR) shall be entered on the patient record.

The provision does not indicate who is responsible for this documentation. Again the value of the most responsible physician concept could be used to advantage.

> 7) Advance care plans should be reviewed with patients, or appropriate others, whenever health status, prognosis, or preferences change.

It is not clear why the word "should" is used in this provision. In our view, "shall" is preferable. "Appropriate others" is vague and again the review would most appropriately be made by the "most responsible physician".

> 8) Patients, or appropriate others, have the right to request an additional opinion from appropriately qualified physicians and should be informed of this right.

As noted earlier, we believe that health care institutions have a special responsibility to assist patients in their exercise of this right.

> 9) Physicians will consider the use of ethics consultation services, or mediation services, if agreement between a physician and patient, or legal surrogate, cannot be reached.

The words "will consider" weaken this provision unduly. Furthermore there is unevenness of language between "legal representative" used earlier in the document and "legal surrogate" in this provision.

Our purpose here is not to embark on a detailed analysis or criticism of this protocol. It is, however, exemplary of a significant challenge in the area of end of life medical decision making. There are a number of bodies that have or are revising end of life medical decision making protocols without any central coordination or consultation. While there may be some consistency in the general policy direction of these various initiatives, there is no consistency in language or procedures. This is illustrated by the WRHA policy. It is reasonably compatible with the College's sample Policy but the language is not uniform, the principles enunciated contain a broader discretion for physicians in their decision making, the obligations of health care professionals are less well defined, there is some lack of clarity as to the allocation of ultimate responsibility for aspects of the process and there is somewhat less emphasis on patient autonomy. This lack of coordination and consistency is likely a feature of the policies and protocols in other provincial health authorities and health care institutions. In our view, consistency among institutions and across the province is a high priority.

The most attractive resolution to this problem is to promote a voluntary recognition and acceptance by all health care authorities, agencies, organizations and institutions of *the College's Policy once finalized in a manner that is consistent with our recommendations and embodied in a by-law or statement as an authoritative template for all institutional and organizational policies and protocols.* It is not, of course, within the power of the College to dictate to health care institutions. Nevertheless, all health care institutions have a responsibility to facilitate the ethical practice of medicine and to create an environment which permits physicians to comply comfortably with their professional duties. Furthermore, the College's proposed Policy is consistent with the growing consensus that the primary goal of any policy is to implement a consultative approach designed to achieve an agreement between the parties. Consequently, it is desirable that all health care authorities and institutions adopt policies and protocols which recognize and are consistent with the final version of the College's Policy.

We also believe that health care institutions have some additional responsibilities to their patients to ensure the full implementation of the College's Policy. We noted them earlier but repeat them here for the sake of clarity.

1. The Policy contemplates the use of institutional mediators, conciliators and facilitators to assist the parties where they are unable to reach a consensus on the withholding or withdrawal of life sustaining medical treatment. It also recognizes the possibility of using external third party mediators. We believe that it is the obligation of the physician to participate in any reasonable mediation measures that are desired by the patient. There must, however, be strong institutional support to inform, fund and implement the process chosen by the patient or the substitute decision maker. The institutional policy must be pro-active and the responsibility for implementing appropriate procedures must be assigned to specific employees or officers of the institution. Complete and timely information on all alternative dispute settlement options available is vital.

2. The Policy provides for an independent second medical opinion where there is a failure of consensus. To exercise this option sensibly, a patient or substitute decision maker will often need information, advice and assistance. For example, patients may need to know the names of other specialist physicians and be informed as to how they may be contacted. The logistics of securing a second opinion, which may appear simple to health care professionals, may prove to be very difficult for a seriously ill patient. The health care institution must take responsibility for facilitating this option. Once again, the institutional policy must be pro-active and the responsibility for assisting a patient in securing an independent second opinion must be assigned to specific employees or officers of the institution. Complete and timely information about this right is vital.

3. The Policy provides for a right of transfer of care of the patient to another physician where there is a failure of consensus. Unless information, advice and assistance are provided to the patient, this may be an illusory option for some patients. Again, this must be an institutional policy with responsibility assigned to specific persons.

4. There is an institutional responsibility in respect of the transparency of end of life decision making policies. It is essential that individual patients facing such personal decision making and the Manitoba public in general have full and complete information of how these decisions are made and the protocols that guide that process. This requires not merely the availability of such information, it requires a well financed educational campaign to disseminate this information to the widest possible audience. This will help to dispel individual anxiety and suspicion and the erosion of public trust that is the product of end of life medical decision making policies, procedures which are not open for public scrutiny.

These institutional obligations are complementary to and not in derogation of the obligations of physicians under the Policy. The availability of alternative dispute resolution, the right to a second opinion and the right to a transfer of care must all be discussed and offered by the physician. The logistics of implementing such options will involve the health care institution. The physician may have to play a more substantial role in this respect where the patient is not in a health care institution.

CHAPTER 8

RECOMMENDATIONS

Our final recommendations are influenced by the fact that end of life decision making is the current focus of a number of bodies that have recently or are currently reviewing policies and re-writing protocols to assist health care professionals and patients to resolve these issues in a compassionate, informed and sensitive process designed to achieve consensus in the great majority of cases. Furthermore, we are very much aware that the Policy of the College of Physicians and Surgeons of Manitoba is a work in progress and we are unable to predict the final product and the extent to which our views will be reflected in it. Nevertheless, we recognize the time, effort and progress that is being made by health care institutions and organizations and we further recognize that much of the work is in a direction that is compatible with our formulation of general principles and policies. At this stage, we believe that our most valuable contribution is not to make recommendations to government for an authoritative legislative regime but rather to provide advice to those bodies and institutions who are formulating end of life policies in respect of the principles that should inform their work, about the kind of protocols that should be put in place and on the importance of a high degree of consistency among health care institutions across the province. In particular, we recommend:

RECOMMENDATION 1

That the sample Policy of the College of Physicians and Surgeons of Manitoba be amended to take into account the individual suggestions made in the text of this Report and that the Policy be formulated as by- laws or statements of the College.

RECOMMENDATION 2

That such by-laws or statements of the College of Physicians and Surgeons of Manitoba on end of life medical decision making be accepted by the health care system and its institutions, agencies and organizations as the definitive and authoritative template for end of life medical decision making.

RECOMMENDATION 3

That health care institutions, agencies and organizations across the province review their protocols and procedures for end of life decision making to ensure their consistency and compatibility with the anticipated by-laws or statements of the College of Physicians and Surgeons of Manitoba.

RECOMMENDATION 4

That health care institutions, agencies and organizations across the province assume special responsibility to provide, at their expense, information, advice and assistance to patients or substitute decision makers in respect of all reasonable mediation and conciliation dispute resolution measures, the securing of independent second medical opinions or the transfer of care to other physicians. The dispute resolution measures should include institutional and external mediation and conciliation procedures. The institutions and the most responsible physicians should cooperatively accommodate all reasonable requests by patients or the substitute decision makers for such measures. We are reluctant to stipulate more definitively the nature of the mediation procedures to be used because of the differences in the size, nature and resources of health care institutions across the province.

RECOMMENDATION 5

That all persons, agencies, organizations and associations involved in the delivery of health care work cooperatively to develop and deliver an informational and educational program to all Manitobans explaining fully the responsibilities, rights and procedures for end of life decision making.

We recognize that these recommendations are not for *law* reform in the strict sense. Some legislative intervention may be necessary in the future if the medical practice of physicians and the protocols of institutions evolve in a manner that is significantly incompatible with the views that we have expressed. Nevertheless, it is fair to record that, at this stage, we would be reluctant to recommend a legislative regime dictating end of life medical decision making procedures to physicians and health care institutions. There are a number of reasons for this.

First, such legislation would be very difficult to draft in the light of the diversity of circumstances in which these issues arise. Secondly, there are difficult issues of enforcement and penalties for a breach of such legislation. Thirdly, the legislature has designated the College of Physician and Surgeons of Manitoba as the appropriate body to control the practice of medicine in the public interest. In so doing, it has indicated that it has no desire to micro-manage medical practice. Finally, legislation runs the risk of future inconsistency with the evolving professional and ethical obligations of physicians. We would recommend legislation only when the protocols and practices are significantly inconsistent with the principles that we have outlined above.[4]

It may be argued that even if our recommendations are accepted there is still no legal certainty. There will be no authoritative judicial or legislative ruling and dissatisfied patients and substitute decision makers will continue to litigate disputes that have not been resolved by the contemplated measures. It is our view, however, that the implementation of a transparent and accountable system of end of life medical decision making that is consistent with the recommendations contained herein is likely to be accepted and validated by the courts.

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[4] For an example of such legislation see: *Advanced Directives Act 1999*, §166.001-166.166 of Tex. *Health and Safety Code*

At the same time, as previously noted, our review has convinced us that the issue of substitute decision making does require legal solution, and we will address that issue in a separate Report.

This is a Report pursuant to section 15 of *The Manitoba Law Reform Commission Act*, C.C.S.M. c. L95, signed this 18th day of December 2003.

Clifford HC Edwards

Clifford H.C. Edwards, President

John Irvine

John C. Irvine, Commissioner

Gerald O. Jewers, Commissioner

Kathleen C. Murphy, Commissioner

Alice R. Krueger

Alice R. Krueger, Commissioner

APPENDIX A

MANITOBA LAW REFORM COMMISSION DISCUSSION PAPER ON WITHHOLDING OR WITHDRAWING LIFE-SUSTAINING TREATMENT

(June 2002)

TABLE OF CONTENTS

Page #

CHAPTER 1 - INTRODUCTION 1
- A. SCOPE OF DISCUSSION PAPER 2
- B. CONCEPTS AND TERMINOLOGY 2
- C. INVITATION TO COMMENT 6

CHAPTER 2 - THE LAW IN CANADA 7
- A. CONSENT GENERALLY 7
- B. THE RIGHT TO REFUSE VERSUS THE RIGHT TO DEMAND 8
- C. IS THERE A LEGAL BASIS FOR THE RIGHT TO TREATMENT? 12
- D. CONCLUSION AND ISSUES FOR DISCUSSION 18

CHAPTER 3 - THE LAW ELSEWHERE 19
- A. ENGLAND 19
- B. UNITED STATES 22
- C. CONCLUSION 26

CHAPTER 4 - MAKING DECISION TO WITHDRAW OR WITHHOLD LIFE-SUSTAINING TREATMENT 27
- A. MEDICAL ETHICS AND THE PHYSICIAN-PATIENT RELATIONSHIP 27
- B. DECIDING ON THE BASIS OF FUTILITY 29
  - 1. Why Do Patients Request Futile Treatment? 32
  - 2. Futility and the Disabled 34
  - 3. Futility and the Elderly 35
  - 4. Religion, Culture and Race 36
- C. DNR POLICIES IN MANITOBA 39
- D. ECONOMIC CONSIDERATIONS: SHOULD THEY BE RELEVANT? 40

CHAPTER 5 - ISSUES FOR DISCUSSION 42

CHAPTER 1

INTRODUCTION

Advances in medical technology and knowledge have developed (and continue to do so) at a rapid pace resulting in the ability to prolong life in circumstances which would have been impossible a relatively short while ago. Now that we have the ability to prolong life, we are faced with the question of whether we should do so.

As new technologies became available, the medical profession used them to full advantage to preserve and prolong life. On the other hand, not all patients wanted aggressive life-sustaining treatment and so began the "right to die" movement. It advocated for greater patient autonomy and the right to refuse life-sustaining treatment, a right which has now been recognized in Canadian law.[5]

As a result of their experience with the aggressive application of life-sustaining techniques and technologies, the medical profession came to realize that, for certain kinds of patients, the treatment had little effect and, in some cases, caused more harm in terms of suffering and indignity. It is now recognized that the aggressive administration of life-sustaining treatment, without weighing the possible harm against the possible benefit, violates ethical principles. In response, the profession has developed guidelines under which health care providers may withhold or withdraw (i.e., discontinue) life-sustaining treatment, in some cases without the consent of the patient and, at times, without their knowledge.

The debate has now shifted from the right to refuse life-sustaining treatment, which is clearly established, to the right to demand it when health care providers have determined that it is no longer appropriate. This latter "right" is not recognized by either the medical profession or at law. In fact, there is much confusion in the law about the respective rights and obligations of patients and health care providers in making decisions to withdraw or withhold life-sustaining treatment. Disputes between health care providers and patients have received a great deal of media attention and have generated public discussion. If media reports are any indication, Manitobans are unhappy with the current practice.

Professional medical guidelines and the common law, as it currently stands, give health care providers the balance of power in deciding whether to withhold or withdraw life-sustaining treatment. The source of this authority is found in the concept of futility. Health care providers are not obliged to offer or administer treatments that are, in their opinion, "futile". Futility, as a basis for end-of-life decision making, is a controversial concept because there is no generally accepted understanding of what it means.

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[5] *Ciarlariello* v. *Schacter* [1993] 2 S.C.R. 119; *Malette* v. *Shulman* (1990), 67 D.L.R. (4th) 321 (Ont. C.A.); *N.B.* v. *Hôtel-Dieu de Québec* (1992), 86 D.L.R. (4th) 385 (Qué. Sup. Ct.).

The health care provider's power to decide seems at odds with the concept of patient autonomy and many people are concerned about their "loss of voice"[6] in the health care process. On the other hand, health care providers are concerned that increased patient control negatively impacts their professional integrity and authority to make clinical judgments. In order to satisfy the general public and the medical profession, the following broadly based issues need to be addressed:

(1) In what circumstances is it appropriate to withhold or withdraw life-sustaining treatment?
(2) Who should decide when it is appropriate?

A. SCOPE OF DISCUSSION PAPER

To facilitate public discussion and community/stakeholder input on these issues, the Commission reviews the current statute and common law in Canada, England and the United States. We then discuss the current practice and policy with respect to end-of-life decision making and the conflict between patients and health care providers. We devote part of the discussion to the concept of futility and the controversy around the concept as the basis for decisions to withdraw or withhold treatment and for the physician's authority to make such decisions. Particular attention is paid to the potential misuse of futility judgments with respect to the disabled and the elderly and the potential for discrimination on the basis of race, religion and culture.

We ask a number of questions throughout the paper to which we hope community and stakeholder groups will provide their views.

This paper is limited to discussion of the right to demand life-sustaining treatment and the legal authority for withdrawing or withholding life-sustaining treatment contrary to or without the consent of the patient. Much has been written on other end-of-life issues such as euthanasia and assisted suicide and it is not our intention to try to add to that debate here.

B. CONCEPTS AND TERMINOLOGY

The following legal and medical terms are frequently used in the discussion paper.

Futile or Futility

We will use the term "futile" in reference to medical care which is useless or ineffective. We refer to two types of medical futility:

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[6] Health Care Ethics Consortium of Georgia, *1997 Task Force on Futility Report* (January 1997) 4 (hereinafter referred to as "HCECG Futility Report), online: <http:// www.hcecg.org> (date accessed: 7 May 2002).

(a) Physiological futility (also referred to as quantitative futility) - A treatment which cannot achieve the desired goal or, in short, one which *will not work*. Physiological futility judgments are believed to involve consideration of pure and objective scientific facts and are presumed to be "value-free". Proponents of medical futility suggest that such judgments can only be made by health care providers as they require the application of clinical judgment and expertise.

(b) Qualitative futility - A treatment which will not produce a *desirable* outcome or provide a *benefit* for the patient or, in short, one which is *not worth doing*. This type of futility judgment is presumed to be "value-laden" as the determination of what is a desired outcome or what constitutes a benefit requires a value judgment. Since values vary from person to person and such decisions require consideration of subjective and non-scientific facts, these judgments should only be made by the patient. Only the patient can decide whether a treatment is worth doing.

Health Care Provider

Any person or institution providing health care services with the power or responsibility to make decisions about patient care.

Patient

Any consumer of health care services and also includes a substitute decision-maker. A substitute decision-maker could include a court appointed committee, the Public Trustee, a health care proxy or a close relative (spouse, parent, child). We recognize that there will be some cases in which the substitute and the patient may not have identical interests or positions; however, dealing with conflict between patient and substitute decision maker is beyond the scope of this paper.

Cardiopulmonary Resuscitation (CPR)

Includes mouth-to-mouth resuscitation, chest compression, bag-and-mask positive-pressure ventilation, entubation and defibrillation.[7]

Do Not Resuscitate Order (DNR)

A do not resuscitate order (DNR) is an order, notation or other indication placed on a patient's chart which directs health care providers not to perform cardiopulmonary resuscitation if the patient goes into cardiac or respiratory arrest.

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[7] Canadian Medical Association, Canadian Healthcare Association, the Canadian Nurses Association and the Catholic Health Association of Canada, "Joint Statement on Resuscitative Interventions" (1995), 153 CMAJ 1652A.

Incompetent Patient

A patient who, due to his or her youth or mental state, does not have the legal capacity to make decisions about health care. Whether a patient has legal capacity to make health care decisions (or a particular decision) will depend upon the patient's ability to understand information about his or her condition and the possible risks and consequences of proposed treatment.

Life-sustaining Treatment

A medical intervention intended to prolong the patient's life without necessarily reversing the underlying illness or injury or improving their condition (although that may happen). Intervention might include CPR, mechanical ventilation, dialysis, surgery, a feeding tube and intravenous to supply nutrition and hydration, drug therapy and antibiotics.[8]

When we talk about "withholding" life-sustaining treatment, we are referring to a decision not to start treatment that could sustain a patient's life, such as CPR. When we talk about "withdrawing" life-sustaining treatment, we mean a decision to stop a treatment that is sustaining the patient's life. For example, "turning off" a respirator or stopping dialysis treatment.

While there are differences between a decision to withhold and a decision to withdraw treatment, the moral, ethical and sometimes practical considerations underlying such decisions are often closely related and, at times, identical. For simplicity's sake, we use the *terms* interchangeably in this paper (except where the context clearly requires a choice of one or the other) while recognizing that there is a distinction between the two *concepts*.

Palliative Care

Care for individuals and families who are living with a terminal or life-threatening illness. The care is aimed at alleviating physical, emotional, psychosocial, or spiritual suffering rather than curing the underlying disease. It focuses on the comfort of the patient and includes care for the patient's family as well.[9]

Parens Patriae

Literally translated means "parent of the country" and refers to the traditional role of the Crown as guardian of persons under a legal disability including children, mentally incompetent adults and any person who, for any reason, is unable to act on his or her own behalf.[10] This power is now vested in the Manitoba Court of Queen's Bench and was described by the Supreme Court of Canada as having broad application, limited only by the best interest of the person in need of protection.[11]

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[8] American Medical Association, *Life Sustaining Procedures*, online: <http://imc.gsm.com/demos/dddemo/consult/lifesust.htm> (date accessed: 25 February 2002).

[9] Special Senate Committee on Euthanasia and Assisted Suicide, *Of Life and Death* (June 1995) 14.

Permanent Vegetative State

A state of eyes-open unconsciousness with sleep-wake cycles in which the patient is incapable of awareness of themselves or their environment. A permanent vegetative state can result from a traumatic injury (car accident, assault) or a non-traumatic injury (stroke). Patients are less likely to regain consciousness after three months in a permanent vegetative state due to a non-traumatic injury or 12 months after a traumatic injury. The patient's brain continues to function to allow independent breathing and heart function so that the patient may not require life support. The average life expectancy of a patient in permanent vegetative state is 2-5 years.[12]

Therapeutic Privilege

An exception to the rule that a health care provider must tell the patient about all material risks associated with a procedure. A health care provider may withhold or generalize information about risks when full disclosure might cause psychological or physical harm to the patient.

The legal validity of the privilege in Canada is uncertain. The Supreme Court of Canada referred to it in *Reibl* v. *Hughes*;[13] however a subsequent Ontario trial Court decision held that the privilege is not recognized in Canadian law.[14]

Treatment

While we might think of "treatment" as a specific therapy for illness, the medical-legal understanding of the term is a system or process of dealing with a medical condition. Treatment includes "all steps taken to ameliorate, remedy, or lessen the effects of disease, illness, disability or disorder".[15] Treatment includes things that are done as well as things that are not. Thus, withdrawing or withholding treatment forms part of the process or system of dealing with a medical condition.

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[10] *Black's Law Dictionary* (6th ed., 1990) 1114.

[11] *Re Eve* (1986), 31 D.L.R. (4th) 1 (S.C.C.). Mrs. E. sought court approval for a non-therapeutic sterilization of her mentally disabled adult daughter. The Court did not approve the procedure on the grounds that it was not required to protect Eve's physical or mental health and constituted a grave intrusion on Eve's rights.

[12] C. Weijer, "Cardiopulmonary Resuscitation for Patients in a Persistent Vegetative State: Futile or Acceptable?" (1998), 158 CMAJ 491 at 491.

[13] *Reibl* v. *Hughes*, [1980] 2 S.C.R. 880 at 895.

[14] *Meyer Estate* v. *Rogers* (1991), 78 D.L.R. (4th) 307 at 314 (Ont. Gen. Div.). See also B. Sneiderman, J.C. Irvine and P.H. Osborne, *Canadian Medical Law: An Introduction for Physicians, Nurses and other Health Care Professionals* (2nd ed., 1995) 67-68.

C, INVITATION TO COMMENT

We hope that as many people as possible will accept our invitation to write to us and share their thoughts on the issues raised in this Discussion Paper.

Once all comments and opinions have been received, the Commission will consider them and prepare its final Report. In accordance with *The Law Reform Commission Act*, the Report will be submitted to the Minister of Justice and Attorney General for consideration.

Anyone wishing to respond to the issues raised in this Discussion Paper (or to comment on any other relevant issue) is invited to write to the Commission at the following address:

Manitoba Law Reform Commission
1210-405 Broadway
Winnipeg, MB R3C 3L6

Submissions may also be sent by fax to (204) 948-2184 or by e-mail to lawreform@gov.mb.ca. We regret that we are unable to receive oral submissions.

Unless clearly marked to the contrary, the Commission will assume that comments received are not confidential and that respondents consent to the Commission quoting from or referring to their comments, in whole or in part, and to the comments being attributed to them. However, requests for confidentiality or anonymity will be respected to the extent permitted by *The Freedom of Information Act*.

The deadline for submission is September 30, 2002.

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[15] Law Reform Commission of Canada, *Medical Treatment and Criminal Law* (Working Paper #26, 1980) 56.

CHAPTER 2

THE LAW IN CANADA

> I think that many Canadians would have been surprised to learn that a doctor can make a "do not resuscitate order" without the consent of a patient or his or her family, yet that appears to be the current state of the law in Canada, Britain and the United States.[1]

A. CONSENT GENERALLY

At common law every person has the right to consent to medical treatment, which includes the right to accept and to refuse treatment.[2]

> The four components of consent to medical treatment are:
>
> - consent must be given voluntarily
> - a patient must have capacity [to consent]
> - consent must be specific to both the treatment and the person providing it
> - consent must be informed, i.e., the patient must understand the nature of the procedure, the attendant risks and benefits and any alternative treatments.[3]

In Manitoba, consent to treatment for incompetent patients can be obtained in a number of ways. *The Mental Health Act* and *The Vulnerable Persons Living with a Disability Act*[4] allow for the appointment of a substitute decision-maker in certain circumstances. *The Health Care Directives Act*[5] allows an individual to appoint a health care proxy to give consent on his or her behalf; or for the making of a health care directive giving instructions regarding medical treatment. In an emergency, health care providers can administer treatment which is necessary to preserve the patient's life and health. Where no statutorily authorized substitute is available, health care providers will seek consent from a close family member, even though there is no legal authority for family members to give substitute consent.[6] In cases where none of the above methods are available or appropriate, the Court of Queen's Bench may, under its *parens patriae* jurisdiction, consent to medical treatment which is in the patient's best interests.

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[1] *Sawatsky* v. *Riverview Health Centre Inc.* (1998), 167 D.L.R. (4th) 359 at 362 (Man. Q.B.).

[2] *Reibl* v. *Hughes*, [1980] 2 S.C.R. 880 (consent generally); *Malette* v. *Shulman* (1990), 67 D.L.R. (4th) 321 (Ont. C.A.) and *N.B.* v. *Hôtel-Dieu de Québec* (1992), 86 D.L.R. (4th) 385 (Qué. Sup. Ct.) (right to refuse medical treatment).

[3] B. Grainger, E. Margolese and E. Partington, "Legal and ethical considerations in blood transfusion" (1997), 156 CMAJ (11th supp.) S50 at S50-S51.

[4] *The Mental Health Act*, C.C.S.M. c. M110, ss. 28, 61 and 71; *The Vulnerable Persons Living with a Disability Act*, C.C.S.M. c. V90, s. 47.

[5] *The Health Care Directives Act*, C.C.S.M. c. H27, ss. 4-19.

B. THE RIGHT TO REFUSE VERSUS THE RIGHT TO DEMAND

The right to refuse treatment may be characterized as a negative right since it will require health care providers to refrain from treating where consent is not provided. A right to demand life-sustaining treatment would be a positive right since health care providers would be compelled to administer treatment regardless of their opinion as to whether it was appropriate.

While it seems logical to extend the right to refuse life-sustaining treatment to include the right to demand it, the latter (a positive right) does not necessarily flow from the former (a negative right).

> The difference between the demands "don't touch me" and "you must touch me" is dramatic. The law has almost uniformly conceded the former but has only hesitantly recognized the latter, and only in situations related to public health and safety."[7]

Courts have little difficulty recognizing and enforcing negative rights but tend to be reluctant to recognize positive rights, particularly those which require the expenditure of money or other resources by government.[8]

In cases such as *R.* v. *Morgentaler* and *R.* v. *Parker*,[9] the Court held that criminal prohibitions on abortion and marijuana-use deprived individuals of access to treatment. This threatened their life or health and constituted a deprivation of security of the person, contrary to section 7 of the *Canadian Charter of Rights and Freedoms*.[10] These decisions were based on the (negative) right to be free from unreasonable interference in health care decisions but did not recognize a positive right of access to either abortion services or marijuana for medical purposes.

Canadian law has not recognized a legal right to life-sustaining treatment. Certainly, the law, as it currently stands, provides that a health care provider has no duty to provide treatment that is futile and that it is for health care providers to determine when treatment is futile.

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[6] Ontario and British Columbia have enacted legislation which gives family members authority to act as substitute decision makers (*infra* at 12). In a future project, the Commission will consider whether such legislation is required in Manitoba.

[7] W. Pripp and M. Moretti, "Medical Futility: A legal perspective" in M.B. Zucker and H.C. Zucker, eds., *Medical Futility and the evaluation of life-sustaining interventions* (1997) 136 at 139.

[8] See *Dunmore* v. *Ontario (Attorney General)*, 2001 SCC 94 and *Native Women's Assn. of Canada* v. *Canada*, [1994] 3 S.C.R. 627.

[9] *R.* v. *Morgentaler*, [1988] 1 S.C.R. 30; *R.* v. *Parker* (2000), 188 D.L.R. (4th) 385 (Ont. C.A.).

[10] *Canadian Charter of Rights and Freedoms*, being Part I of the *Constitution Act, 1982*, being Schedule B of the *Canada Act 1982* (U.K.), 1982, c. 1 (hereinafter referred to as the *Charter*).

> Based on the case law to date, the courts have stated that a decision not to provide treatment is exclusively within the purview of the doctor and is not a decision to be made by the courts. Thus it appears that the courts would not interfere with a medical decision not to provide treatment.[11]

Two Manitoba cases have considered conflicts between health care providers and patients over DNR orders. In *Re Child and Family Services of Central Manitoba* v. *Lavallee*, the Court of Appeal held that the parental consent was not required and that the physician had the exclusive authority to withhold treatment.

> Whether or not such a direction [DNR] should be issued is a judgment call for the doctor to make having regard to the patient's history and condition and the doctor's evaluation of the hopelessness of the case. The wishes of the patient's family or guardians should be taken into account, but neither their consent nor the approval of a court is required.[12]

The case involved an 11-month old child (D), who had been in a persistent vegetative state since his admission to hospital at the age of three months following a severe beating. It was unlikely that D would ever regain consciousness. He would eventually contract an infection which would require "intrusive heroic measures" to save his life; however, such a procedure would only restore him to an unconscious state. Since continued treatment would not improve D's condition, his doctors wanted to place a DNR order on his chart. Child and Family Services (CFS), who apprehended D from his parents, agreed but the parents did not. As required by legislation, CFS applied for court approval of the DNR order. The Court granted the order finding it to be in D's best interest.

In overturning the lower Court's order, the Court of Appeal relied on the Massachusetts case of *Matter of Dinnerstein*[13] in which the Appeals Court held that it was up to the health care provider to decide to withhold or withdraw treatment and not the Court. In that case, the patient's family consented to the DNR order so the Court did not address conflict between the health care provider and the patient.

A number of commentators have relied upon *Lavallee* to support the proposition that a physician has the exclusive authority to make decisions to withhold or withdraw life-sustaining treatment.[14] However, there are a number of reasons why the *Lavallee* decision cannot and should not be applied beyond the specific facts of this case.[15]

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[11] *Sawatsky* v. *Riverview Health Centre Inc.* (1998), 167 D.L.R. (4th) 359 at 367 (Man. Q.B.).

[12] *Re Child and Family Services of Central Manitoba* v. *Lavallee* (1997), 154 D.L.R. (4th) 409 at 413 (Man. C.A.).

[13] *Matter of Dinnerstein*, N.E. 2d 134 at 413 (1978) (App. Ct. Mass.).

[14] C. Square, "Court verdict 'splendid', ethics professors says" (1998), 158 CMAJ 159, quoting Professor Arthur Shafer, Director of the Centre for Professional and Applied Ethics at the University of Manitoba: "The court ruled that patients or family members (continued...)

Lavallee involved a narrow set of facts: a very young child in a persistent vegetative state, who would certainly die and whose parents' reasons for resisting the DNR order were unclear. The Court did not consider either the *Charter* or *The Human Rights Code* (Manitoba)[16] which are relevant to a broader application of the decision.

This issue arose again in *Sawatsky* v. *Riverview Health Centre Inc.*[17] This case involved an elderly man suffering from Parkinson's disease who was admitted the Riverview Health Centre for rehabilitation and assessment. The admitting physician wanted to place a DNR order on Mr. Sawatsky's chart; however, Mrs. Sawatsky objected and the order was removed.

When Mr. Sawatsky's physician recommended a tracheotomy, Mrs. Sawatsky refused to consent and Riverview obtained an order of supervision under *The Mental Health Act* which effectively replaced Mrs. Sawatsky as substitute decision-maker.[18] A few months later, Mr. Sawatsky contracted pneumonia and his physician, after reviewing his condition and prognosis, placed a DNR order on his chart without consulting or advising Mrs. Sawatsky. The Public Trustee took no position on this decision, in accordance with its policy (developed after the *Lavallee* decision) that consent of the Public Trustee would not be required unless "the proposed course of treatment involves a touching of the patient's person in a non-emergency situation."[19]

Mrs. Sawatsky found out about the DNR order and sought an injunction requiring Riverview to remove it. Justice Beard of the Manitoba Court of Queen's Bench granted an interim injunction and ordered two independent medical assessments of both Mr. Sawatsky's condition and the appropriateness of the DNR order. The issue became moot when Mr. Sawatsky died.

Justice Beard, in her decision to grant the injunction, identified the issues of both private

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[14](...continued)
do not need to be consulted by a physician in DNR cases."

[15] For a detailed critique of the *Lavallee* decision, see B. Sneiderman, "A Do Not Resuscitate Order for an Infant Against Parental Wishes: A Comment on the *Case of Child and Family Services of Central Manitoba* v. *R.L. and S.L.H.*" (1999), 7 Health L.J. 205.

[16] *The Human Rights Code*, C.C.S.M. c. H175.

[17] *Sawatsky* v. *Riverview Health Centre Inc.* (1998), 167 D.L.R. (4th) 359 (Man. Q.B.).

[18] In a strict legal sense, Mrs. Sawatsky did not have authority to act as substitute decision-maker for her husband since Mr. Sawatsky had not designated his wife as his proxy under *The Health Care Directives Act*. In Manitoba, health care providers consult with the next-of-kin, but there is no legal requirement to do so.

[19] Excerpt of a letter from the Public Trustee of Manitoba to Winnipeg hospitals dated December 16, 1997 and quoted in B. Sneiderman, "A Do Not Resuscitate Order for an Infant Against Parental Wishes: A Comment on the *Case of Child and Family Services of Central Manitoba* v. *R.L. and S.L.H.*" (1999), 7 Health L.J. 205 at 208. This policy was the subject of Justice Beard's disapproval in *Sawatsky*, who suggested that the Public Trustee had "completely abdicated" its responsibility to the patient: *Sawatsky* v. *Riverview Health Centre Inc.* (1998), 167 D.L.R. (4th) 359 at 377 (Man. Q.B.). The policy has since been reversed.

and public concern as follows:

> (1) in what factual circumstances can a doctor or health care facility issue a "do not resuscitate" order;
> (2) do those factual circumstances apply in this case;
> (3) can a doctor or health care facility legally issue a "do not resuscitate" order if the patient or the person entitled to consent to health care treatment for the patient refuses to consent to that order?[20]

Justice Beard questioned whether the current legal position was definitive because previous cases did not consider the application of human rights legislation such as the *Charter* or *The Human Rights Code* (Manitoba).

Another Canadian case, *Re London Health Sciences Centre* v. *R.K.*, held that Canadian courts do not have the authority to exempt health care providers from civil or criminal liability for withdrawing treatment and that it was up to legislators to determine policy in this regard.

> If what is being sought is a declaration that a physician has the legal right in these circumstances to withdraw life support from R.K., I am not at all certain that is a declaration a court should make. Questions such as this, involving as they do complex moral, ethical, religious, and legal issues are best dealt with in a multicultural society by Parliament rather than the courts. They lie essentially within the purview of the legislative branch of government, whose function is to decide upon and enumerate policy, and not within that of the judicial branch.[21]

Should a right to life-sustaining treatment be established, and if so, how? It has been suggested that the creation of such a right may

> ... rely solely on statutory law, which is generally the mechanism used to establish positive rights. Indeed, because it is the only method of creating a positive right that compels another individual to touch the person exercising the right, a legal resolution of the futility debate may lie in the hands of the federal and state legislatures....[22]

The suggestion that legislation may be the only way in which a right to life-sustaining treatment can be established has prompted the Commission's review of this issue.

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[20] *Sawatsky* v. *Riverview Health Centre Inc.* (1998), 167 D.L.R. (4th) 359 at 362 (Man. Q.B.).

[21] *London Health Sciences Centre* v. *K.(R.) (Litigation Guardian of)* (1997), 152 D.L.R. (4th) 724 at 734 (Ont. Gen. Div.).

[22] W. Pripp and M. Moretti, "Medical Futility: A legal perspective" in M.B. Zucker and H.C. Zucker, eds., *Medical Futility and the evaluation of life-sustaining interventions* (1997) 136 at 142.

C. IS THERE A LEGAL BASIS FOR THE RIGHT TO TREATMENT?

There is no Manitoba legislation which regulates decisions to withdraw treatment. *The Health Care Directives Act* extends the common law right of consent to treatment so that a patient's wishes with respect to treatment can be honoured after the patient becomes incompetent. The Act does not create any new rights; it merely provides a mechanism for exercising existing rights to consent after incapacity.[23] There is nothing in this Act which requires a health care provider to honour a request for life-sustaining treatment which conflicts with their medical opinion.

Both Ontario and British Columbia have enacted legislation to codify the law of consent to medical treatment. Ontario's *Health Care Consent Act*[24] requires consent for any "treatment" including plans to withhold or withdraw care. Therefore, on a plain reading of the Act, a health care provider cannot withdraw treatment without the consent of the patient. This does not mean, however, that patients can insist on a particular treatment. British Columbia's *Health Care (Consent) and Care Facility (Admission)Act* requires consent to "health care" which does not expressly include a plan to withdraw or withhold treatment, although the definition may be broad enough to include it. The British Columbia Act also provides for "the right to select a particular form of available health care on any grounds, including moral or religious grounds".[25] While somewhat vague, it does suggest that a patient can request life-sustaining treatment on moral or religious grounds.

The *Criminal Code of Canada*[26] regulates medical treatment under the duty to provide the necessaries of life[27] to a person already in care. The Code does not impose a duty on a health care provider to administer treatment. However, once a health care provider undertakes to do so, he or she must use reasonable knowledge, care and skill[28] and must continue to provide treatment where failing to do so could threaten the health or life of the patient.[29]

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[23] *The Health Care Directives Act*, C.C.S.M. c. H27, s. 25: "Nothing in this Act abrogates or derogates from any rights or responsibilities conferred by statute or common law.

[24] *Health Care Consent Act, 1996*, S.O. 1996, c. 2, Schedule A.

[25] *Health Care (Consent) and Care Facility (Admission) Act*, R.S.B.C. 1996, c. 181, s. 4(b).

[26] *Criminal Code of Canada*, R.S.C. 1985, c. C-46.

[27] **215(1)** Everyone is under a legal duty ...
(c) to provide necessaries of life to a person under his charge if that person
(i) is unable, by reason of detention, age, illness, mental disorder or other cause, to withdraw himself from that charge, and
(ii) is unable to provide himself with necessaries of life.

[28] **216** Every one who undertakes to administer surgical or medical treatment to another person or to do any other lawful act that may endanger the life of another person is, except in cases of necessity, under a legal duty to have and to use reasonable knowledge, skill and care in so doing.

A "lawful excuse" constitutes a defence to a charge of failing to provide the necessaries of life.[30] The patient's request to withhold or withdraw treatment is a lawful excuse. *Lavallee* suggests that a health care provider's decision to withhold treatment on grounds of futility would also represent a lawful excuse. This is the law in other common law jurisdictions, such as California, England and New Zealand[31] where withdrawing life sustaining treatment in certain circumstances does not breach criminal or civil law. These decisions are based upon a finding that health care providers have no duty to administer futile treatment.

Human rights legislation, such as the *Charter* and *The Human Rights Code* (Manitoba) may also affect decisions to withdraw or withhold life-sustaining treatment.

The *Charter* provides constitutional protection for certain human rights and freedom from unreasonable *state* interference in the exercise and enjoyment of those rights. Section 32(1) of the *Charter* provides that it applies to government, including "laws, regulations, policies and practices" of government.[32] It does not apply to private bodies or individuals unless they exercise a government function or act as an agent of the government.[33]

Under the Constitution,[34] authority over health care is divided between the provincial and federal governments with the provincial government having the greater control under its power to regulate matters of a "local or private nature".[35] The Province has delegated some authority for the delivery of publicly funded health services to health care providers thus providers may be considered agents of the government to the extent that they are an integral part of the publicly administered and funded health care system.[36] In other functions, such as internal management, they are not bound by the *Charter*. For example, a hospital's personnel policies are exempt from *Charter* scrutiny since the internal management of a hospital is not considered a "government" function or activity.[37] Conversely, in *Eldridge* v. *British Columbia (Attorney General)*;[38] the Supreme Court held that the *Charter* does apply to hospitals when they are engaged in the administration and delivery of health services.

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[29] 217 Every one who undertakes to do an act is under a legal duty to do it if an omission to do the act is or may be dangerous to life.

[30] *Criminal Code of Canada*, R.S.C. 1985, c. C-46, s. 215(2).

[31] *Barber* v. *Superior Court*, 195 Cal. Rptr. 484 (Cal. App. 1983); *Airedale NHS Trust* v. *Bland*, [1993] 1 All E.R. 821 (H.L.); and *Auckland Area Health Board* v. *A.G.*, [1993] 1 N.Z.L.R. 235 (H.C.).

[32] M. Jackman, "The Application of the Charter in the Health Care Context" (2000), 9 Health L. Rev. 22 at 22.

[33] M. Jackman, "The Application of the Charter in the Health Care Context" (2000), 9 Health L. Rev. 22 at 25.

[34] *The Constitution Act, 1867*, 30 & 31 Vict., c. 3 (U.K.).

[35] M. Jackman, "Constitutional Jurisdiction over Health in Canada" (2000), 8 Health L. Rev. 95 at 96.

[36] M. Jackman, "The Application of the Charter in the Health Care Context" (2000), 9 Health L. Rev. 22 at 24.

In Manitoba, the publicly funded health insurance plan covers "all services rendered by a medical practitioner that are *medically required* and which are not specifically excluded by regulation."[39] There is no definition of the term "medically required" and no requirement that health care providers obtain Manitoba Health's approval before undertaking a treatment. Health care providers decide which services are medically required for any given patient which means that they control the patient's access to the publicly funded health care system. As suggested above, health care providers are bound by the *Charter* in exercising this public function.

The *Charter* rights which are most relevant to the provisions of health care services are the right to life, liberty and security of the person (Section 7)[40] and the right to equality before and under the law and to equal protection of the law (Section 15(1)).[41]

Section 7 protects the right of self-determination in health care and has been described as a fundamental right at common law.[42] This right of self-determination is part of the right to security of the person and encompasses the right to determine what medical procedures will be accepted and the extent to which they will be accepted. The right to decide what is to be done to one's own body includes the right to be free from medical treatment to which the individual does not consent. Section 15(1) of the *Charter* prohibits discrimination on both the listed and any analogous grounds.[43]

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[37] *Stoffman* v. *Vancouver General Hospital*, [1990] 3 S.C.R. 483. A physician challenged the hospital's mandatory retirement policy. The Court held that the hospital was a private entity for the purposes of internal hospital management and was not subject to *Charter* review of its personnel policy.

[38] *Eldridge* v. *British Columbia (Attorney General)*, [1997] 3 S.C.R. 624.

[39] *The Health Services Insurance Act*, C.C.S.M. c. H35., s.2(1) (definition of "medical services"); *Medical Services Insurance Regulation*, M.R. 49/93, s. 1 (definition of "insured medical services"). See also *Excluded Services Regulation*, M.R. 46/93. For judicial consideration of the term "medically required", see *Cameron* v. *Nova Scotia (Attorney General)* (1999), 177 D.L.R. (4th) 611 (N.S.C.A.) (challenge of the refusal to fund out-of-province fertility treatments).

[40] Everyone has the right to life, liberty and security of the person and the right not to be deprived thereof except in accordance with the principles of fundamental justice.

[41] Every individual is equal before and under the law and has the right to the equal protection and equal benefit of the law without discrimination and, in particular, without discrimination based on race, national or ethnic origin, colour, religion, sex, age or mental or physical disability.

[42] *Ciarlariello* v. *Schacter* [1993] 2 S.C.R. 119. A patient panicked during a medical procedure and told the doctor to stop. After further discussion with the doctor, she consented to continue; however, she suffered a reaction and was rendered a quadriplegic.

[43] In *Law Society of British Columbia* v. *Andrews*, [1989] 1 S.C.R. 143, the Supreme Court of Canada held that the list of prohibited grounds of discrimination in s. 15(1) is not "exhaustive" and can include "analogous" (related or similar) grounds. The

(continued...)

Charter rights are subject to some limits to ensure that the exercise of rights by one person does not infringe on the rights of another. Accordingly, under section 1, all *Charter* rights are subject to reasonable limits which are "demonstrably justified in a free and democratic society." Section 7 rights are also subject to limits in accordance with "principles of fundamental justice". Limits on the rights of self-determination in health care have been recognized or proposed in the following situations:

- where refusing treatment might endanger the life or health of another person;[44]
- where the exercise of autonomy might offend public policy; for example, the sale or donation of one's organs while living;[45]
- consenting to have death "inflicted" (euthanasia or assisted suicide).[46]

Withholding or withdrawing life-sustaining treatment without the patient's consent will violate the patient's right to life and security of the person because the patient may die and is deprived of control over their bodily integrity. The next question to consider is whether the deprivation of this right is in accordance with principles of fundamental justice.

In *Rodriguez*, Justice Sopinka described principles of fundamental justice as those which are vital to our societal notion of justice. The difficulty with recognizing a right to treatment is that it creates a positive obligation on the health care provider. It requires the health care provider to do something that may go against his or her professional judgment. Is a health care provider's right of professional integrity protected by the *Charter*? If there is such a right, then any right to treatment would have to be balanced against it.

Whether *The Human Rights Code* (Manitoba),[47] affects decisions to withdraw or withhold treatment depends on whether medical treatment is covered by the HRC. The goal of the HRC is to ensure *equality of opportunity* for all individuals in the provision of any "service, accommodation, facility, good, right, licence, benefit, program or privilege *available or accessible to the public* or to a section of the public" (emphasis added) [section 13(1)]. The HRC is not intended to regulate a purely private relationship - only those relationships which are open to "the public".

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[43](...continued)
following have been held to be "analogous" grounds: citizenship (*Andrews*); "aboriginality - residence", (*Corbiere* v. *Canada (Minister of Indian and Northern Affairs)*, [1999] 2 S.C.R. 203); marital status (*Miron* v. *Trudel*, [1995] 2 S.C.R. 418); sexual orientation (*Egan* v. *Canada*, [1995] 2 S.C.R. 513).

[44] *Nancy B* v. *Hôtel-Dieu de Québec* (1992), 86 D.L.R. (4th) 385 at 391 (Qué. Sup. Ct.), quoting from Prof. J.L. Beaudoin in "Le droit de refuser d'être traité".

[45] *Nancy B* v. *Hôtel-Dieu de Québec* (1992), 86 D.L.R. (4th) 385 at 391 (Qué. Sup. Ct.), quoting from Prof. J.L. Beaudoin in "Le droit de refuser d'être traité".

[46] *Rodriguez* v. *British Columbia (Attorney General)*, [1993] 3 S.C.R. 519.

[47] *The Human Rights Code*, C.C.S.M. c. H175 (hereinafter referred to as "HRC").

Section 9(1) prohibits discrimination which includes: (a) differential treatment of an individual; and (b) failure to make reasonable accommodation for the special needs of an individual, based on one or more of the listed grounds, set out in section 9(2).[48] An example in the context of health care might be the withdrawal of life-sustaining treatment from an elderly patient solely on the basis of their age.

Section 13(1) provides an exception for discrimination for which there is "*bona fide* [good faith] and reasonable cause."

Whether or not health care providers are subject to the HRC when they are providing (or withholding) medical treatment will depend upon whether those treatments may be considered to be a service, benefit or privilege available to the public. Few cases have addressed this issue directly although at least two have found that certain medical services are available to the public.[49] Certainly, the fact that health care services are publicly funded and administered gives rise to a perception that medical treatment is a "public" service.

The meaning of phrase "services available to the public" has been considered by the Supreme Court of Canada in two cases, neither of which involved medical treatment. In *University of British Columbia* v. *Berg*,[50] a student alleged discrimination on the basis of mental disability when the University withheld a key to the building (all other students received keys) and did not provide her with a "rating sheet" which she needed to secure an internship. In *Gould* v. *Yukon Order of Pioneers*,[51] the Court considered whether restricting membership in a fraternal society to men was prohibited discrimination. Justice La Forest's reasons for decision (the majority decided the case on other grounds) on whether membership was a service available to the public offers some useful comments on the nature of public and private services.

Assuming that decisions to withhold treatment fall within the scope of the HRC, a complainant (or more likely their estate) would have to establish that the decision constitutes discrimination on the basis of age, disability or one of the other grounds and that such discrimination is neither reasonable nor in good faith.

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[48] The prohibited grounds of discrimination are set out in s. 9(2) and include ancestry (including colour and perceived race); nationality or national origin; ethnic background or origin; religion or creed, or religious belief, religious association or religious activity; age; sex, (including pregnancy, the possibility of pregnancy, or circumstances related to pregnancy), gender-determined characteristics or circumstances; sexual orientation; marital or family status; source of income; political belief, political association or political activity; and physical or mental disability or related characteristics or circumstances.

[49] *Korn* v. *Potter* (1996), 134 D.L.R. (4th) 437 (B.C.S.C.) (refusal to provide artificial insemination services to lesbian women was discrimination contrary to the *Human Rights Act*, S.B.C. 1984, c. 22); *Hinkel* v. *Wood*, [1993] B.C.C.H.R.D. No. 24, online: QL (BCHR) (dental services were considered to be customarily available to the public).

[50] *University of British Columbia* v. *Berg*, [1993] 2 S.C.R. 353.

[51] *Gould* v. *Yukon Order of Pioneers*, [1996] 1 S.C.R. 571.

Various commissions and committees have considered end-of-life decision making and the appropriate legislative response. In the 1983, the Law Reform Commission of Canada[52] recommended amending the *Criminal Code* to exempt health care providers who complied with their patient's refusal of life-sustaining treatment from criminal liability. The proposed amendment, which was not implemented, would have also authorized withholding treatment which was "therapeutically useless" and contrary to the patient's best interest. The Commission did not consider the impact of such an amendment on a patient who wanted life-sustaining treatment contrary to the advice of their health care provider.

In 1995, the Special Senate Committee on Euthanasia and Assisted Suicide released its report entitled: *Of Life and Death* The Committee identified the legal uncertainty surrounding end-of-life decision making and recommended:[53]

(a) formulation of national guidelines governing the withholding and withdrawing of life-sustaining treatment;
(b) amendment of existing guidelines to match national guidelines;
(c) enactment of legislation to recognize and clarify the circumstances in which the withholding and withdrawal of life-sustaining treatment is legally acceptable.

The Committee identified Health Canada as the body which should establish national guidelines in consultation with the provinces and territories and the relevant professional associations. In June, 2001, the federal government announced the creation of Health Canada's Secretariat on Palliative and End-of-Life Care and the provision of funding to coordinate the development of a national strategy on end-of-life care. It appears that the focus of the Secretariat will be improving the quality and availability of palliative care rather than implementing the recommendations to create national guidelines on withholding and withdrawing treatment.

In the report, the Committee addressed the issue of patient consent stating that treatment should not be withheld or withdrawn without the patient's consent unless such treatment is "futile". Futility, the Committee stated, should be narrowly defined as treatment that is, in the opinion of the health care provider, completely ineffective. Unfortunately, this reliance on futility is not very helpful, as discussed below.

In June 2000, the subcommittee of the Standing Senate Committee on Social Affairs, Science and Technology issued its follow up report to *Of Life and Death*.[54] The subcommittee noted that none of the recommendations had been implemented but identified one development.

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[52] Law Reform Commission of Canada, *Euthanasia, Aiding Suicide and Cessation of Treatment* (Report #20, 1983) 32.

[53] Special Senate Subcommittee on Euthanasia and Assisted Suicide, *Of Life and Death* (June, 1995) 46.

[54] Standing Senate Committee on Social Affairs, Science and Technology, "Quality End-of-Life Care: The right of every Canadian" (June 2000), report of the subcommittee of the, online: < http://www.parl.gc.ca/36/2/parlbus/commbus/senate/com-e/upda-e/rep-e/repfinjun00-e.htm> (date accessed: 9 May 2002).

In 1999, the Canadian Healthcare Association, Canadian Medical Association, Canadian Nurses Association, and Catholic Health Association approved the *Joint Statement on Preventing and Resolving Ethical Conflicts Involving Health Care Providers and Persons Receiving Care*.[55] The Joint Statement addresses decisions to withhold and withdraw treatment.

D. CONCLUSION AND ISSUES FOR DISCUSSION

Canadian law does not clearly address end-of-life decision-making and there is much uncertainty regarding the respective rights and obligations of health care providers and patients. This leads to the following questions (with respect to which the Commission hopes to receive input)

Question 1: What should be the nature or form of legal rules governing decisions to withdraw and withhold life-sustaining treatment?

For example:

(a) legislative guidelines (statutes or regulations to existing or new legislation)?
(b) amendments to existing professional guidelines?
(c) other?

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[55] Canadian Healthcare *Association, et al* "Joint Statement on Preventing and Resolving Ethical Conflicts Involving Health care Providers and Persons Receiving Care" (June 15, 1999), on line: <http://www.canadian-healthcare.org/chapol/joint.htm> (date accessed: 7 May 2002).

CHAPTER 3

THE LAW ELSEWHERE

A. ENGLAND

At English common law, no one may administer medical treatment without the patient's consent. No one may give consent to medical treatment on behalf of another adult. Unlike Canada, there is no mechanism by which consent can be given on behalf of an incompetent patient and the English Court no longer has *parens patriae* jurisdiction over mentally incompetent patients.[1] This has created a gap in the law of consent and would mean that incompetent patients would have no access to medical treatment. This gap has been resolved by common law rules which set out the conditions under which a health care provider may treat a patient who cannot give consent. A health care provider may administer treatment that is, in his or her opinion, necessary and in the patient's best interest.[2] In determining what is in the patient's best interest, the health care provider must exercise their discretion in accordance with a "respected body of medical opinion".[3]

If the health care provider determines that treatment is no longer in the patient's best interest, the condition precedent to his or her authority to administer treatment is gone and the health care provider must withdraw the treatment. Thus, the House of Lords decided in *Airedale NHS Trust v. Bland,*[4] that health care providers would not be criminally or civilly liable for withdrawing treatment from a patient in a permanent vegetative state, when continued treatment was not, in the health care provider's opinion, in the patient's best interest. The patient's family agreed with the decision to withdraw treatment so there was no dispute between the health care provider and the patient.

The patient in *Bland* had been in an permanent vegetative state for 31/2 years and there was no possibility that he would regain consciousness as his cerebral cortex had disintegrated. Without the cortex, he could not experience any sensation or thought. The House of Lords accepted that continued existence in a permanent vegetative state was not a "benefit" and therefore continued treatment was not in the patient's best interest.

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[1] *Airedale NHS Trust* v. *Bland*, [1993] 1 All E.R. 821 at 882 (H.L.) (see judgment of Lord Browne-Wilkinson for an explanation of how English courts lost *parens patriae* jurisdiction).

[2] *F.* v. *West Berkshire Health Authority*, [1989] 2 All E.R. 545 (H.L.) (authorizing the sterilization of a mentally incompetent woman).

[3] *Bolam* v. *Friern Hospital Management Committee*, [1957] 2 All E.R. 118 (Q.B.) (involving a claim for damages arising out of electro-convulsive therapy).

[4] *Airedale NHS Trust* v. *Bland*, [1993] 1 All E.R. 821 (H.L.) (this case report contains the decisions at all levels including Family Division, Court of Appeal and House of Lords).

The House of Lords recognized that there is a great division in social opinion on the moral and ethical aspects of the withdrawal of treatment. For that reason, the Court held that decisions to terminate treatment for a patient in a permanent vegetative state should be subject to review and endorsement by the court for "the protection of patients, the protection of doctors, the reassurance of the patients' families and the reassurance of the public."[5] While clearly acknowledging the expertise of doctors in determining which treatments are in a patient's best interest, the court acknowledged that in decisions to terminate treatment there were "exceptional circumstances" which required guidance from the court.

> .. [I]n the absence of an application, the doctor who proposes the cessation of life-supporting care and treatment on the ground that their continuance would not be in the patient's best interest will have reached that conclusion himself and will be judge in his own cause unless and until his chosen course of action is challenged in criminal or civil proceedings.[6]

The law with respect to the right of a *competent* patient to demand life-sustaining treatment is unclear and has not been directly addressed at common law or by statute in England. The British Medical Association has tried to close this gap in the law with guidelines governing the withdrawal and withholding of treatment.[7] Although these guidelines are not "law", English courts pay great deference to professional standards and practice, thus such guidelines are likely to have great influence in any case.[8]

The guidelines allow physicians to withdraw or withhold medical treatment from patients who have "no prospect of recovery", subject to a review by a "senior clinician from outside the treatment team"[9] (this does not apply to patients in a permanent vegetative state or similar condition as per *Bland*).

In making a decision, the health care providers must consider whether treatment will "produce the desired benefit" [11.1(a)] which is defined as "restoring or maintaining the patient's health" [1.1]. If treatment cannot provide this benefit and there is no other reason to provide the treatment, it may be "ethically and legally" withdrawn [1.1].

The patient's view about what constitutes a benefit will "carry considerable weight" and the guideline encourages health care providers to honour *reasonable* requests for treatment, if only for a short time, to allow the patient to sort out their affairs, say goodbye to family and friends, etc. [11.1(a)]. While consideration of patient's wishes and goals is encouraged, the BMA maintains that the health care provider is the ultimate authority [11.1(a) and 18.3]. Where the primary physician's decision is "seriously challenged", the guidelines suggest that a court review is advisable [18.4].

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[5] *Airedale NHS Trust* v. *Bland*, [1993] 1 All E.R. 821 at 862 (H.L.) per Lord Keith.

[6] *Airedale NHS Trust* v. *Bland*, [1993] 1 All E.R. 821 at 876 (H.L.) per Lord Lowry.

[7] British Medical Association, *Withdrawing and Withholding Life-Prolonging Medical Treatment: Guidance for Decision Making* (2nd ed., 2001), online: BMJ Publishing Group Homepage: < http://www.bmjpg.com/withwith/ww.htm> (last modified: 24 April 2001). Note: relevant guidelines are identified in the text in square brackets.

[8] *Airedale NHS Trust* v. *Bland*, [1993] 1 All E.R. 821 at 871-872 (H.L.) per Lord Goff.

[9] British Medical Association, press release, Wednesday, June 23, 1999. See also guideline 22.1(a).

The guidelines address the allocation of scarce resources and recognize that providing life-prolonging treatment to patients who will receive no benefit may affect the resources available to treat other patients [11.1(d)]. The guidelines suggest that courts will not require health care authorities to disregard cost concerns in treatment decisions. This view is supported in *R.* v. *Cambridge Health Authority, Ex. p. B*[10] in which the English Court of Appeal did not interfere with a health care authority's decision not to fund a third round of cancer treatment for a young patient.

The British Medical Association has also established guidelines for CPR which address DNR orders.[11] The DNR guidelines suggest a general presumption in favour of performing CPR unless the patient is in the final stages of a terminal illness or where the burden to the patient outweighs the benefits. The DNR guidelines specifically refer to the English *Human Rights Act, 1998* and confirm that DNR policies and decisions must conform to the rights established by the Act. *The Human Rights Act, 1998* incorporates the majority of humans rights contained in the *European Convention on Human Rights*[12] into English law. Like the *Charter*, this Act requires that public authorities act in accordance with certain human rights[13] and that all statutes be interpreted in accordance with those rights.

Public authorities expressly include "the Department of Health, health authorities, Health Trusts, Primary care Groups and Trusts in England, Primary Care Trusts in Scotland, Local Health Groups in Wales and the equivalent bodies, still to be established, in Northern Ireland." The BMA takes the position that individual doctors working for the National Health Service are bound and that private doctors "may" also be included. The BMA goes on to suggest that even if private doctors are not considered public authorities for the purposes of the Act, good practice requires that their decisions comply with it.[14]

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[10] *R.* v. *Cambridge Health Authority, ex parte B.*, [1995] 2 All E.R. 129 (C.A.).

[11] British Medical Association, "Decisions Relating to Cardiopulmonary Resuscitation: A Joint Statement from the British Medical Association, the Resuscitation Council (U.K.)., and the Royal College of Nursing" (March, 2001), online: <http://bma.org.uk> (date accessed: 7 May 2002) (hereinafter referred to as" DNR guidelines").

[12] British Medical Association, "The Impact of the Human Rights Act 1998 on medical decision making" (October 2000), online: <http://web.bma.org.uk> (date accessed: 7 May 2002).

[13] Including rights to life, security of the person, respect for privacy, freedom from torture and inhuman or degrading treatment, freedom of thought, conscience and religion, freedom of expression and the freedom from discrimination in the exercise of these rights.

[14] British Medical Association, "The Impact of the Human Rights Act 1998 on Medical Decision Making" (October 2000), on line: <http://web.bma.org.uk> (date accessed: 7 May 2002).

Recognizing the difficulty in defining "futility" with precision, the DNR guidelines set out a number of a factors to be considered when determining whether DNR orders are appropriate. For example:

- when CPR will not restart heart and breathing;
- where death is imminent and life can only be restored for a short time or where patient will have no awareness and therefore no ability to experience benefit;
- where burdens outweigh benefits such as injuries form the CPR itself (fractured ribs and sternum, ruptured spleen.[15]

While both the DNR guidelines and guidelines for withdrawing treatment are helpful in setting out criteria for decision making, they do give the balance of power and authority to health care providers and provide few mechanisms for challenging the health care provider's decision. This may perhaps reflect a more paternalistic approach to the physician-patient relationship in England compared to Canada, which has moved towards greater patient autonomy.

B. UNITED STATES

The law relating to withholding and withdrawing of life sustaining treatment in the United States suffers from the same lack of clarity as that in Canada and England. Each state is responsible for the regulation of health care and may approach regulation of end-of-life decision making within DNR, advance directive or other legislation. The national legislative picture looks like a patchwork quilt with many similarities and differences between the various states.

In most states with legislation, there is an attempt to maximize the patient's right of autonomy; however, this is often limited by legislative deference to the health care providers expertise, particularly in making treatment decisions.

A number of states have enacted legislation which gives health care providers authority to refuse requests for futile care. For example, Virginia's *Health Care Decisions Act*[16] provides that health care providers are not required to provide medical treatment which is, in their opinion, medically or ethically inappropriate. This would appear to give health care providers the authority to withhold or withdraw treatment although it has, in at least one case, been held to be subordinate to federal legislation which prohibits discrimination in treatment.[17]

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[15] British Medical Association, "Decisions Relating to Cardiopulmonary Resuscitation: A Joint Statement from the British Medical Association, the Resuscitation Council (U.K.)., and the Royal College of Nursing" (March, 2001), online: <http://bma.org.uk> (date accessed: 7 May 2002).

[16] *Virginia Code*, § 54-1- 2990.

The *Uniform Health-Care Decisions Act*,[18] which has been adopted in whole or in part by Maine, New Mexico, Mississippi and Delaware provides that health care providers may refuse to comply with an advance directive that "requires medically ineffective health care or health care contrary to generally accepted health-care standards applicable to the health care provider or institution.

At least 11 states permit requests for treatment in an advance directive.[19] Indiana and North Dakota recognize a legal right to receive medical treatment which can be communicated by either a "Life Prolonging Procedures Declaration" or a living will.[20] Indiana expressly permits requests for artificial nutrition and hydration "even if the effort to sustain life is futile or excessively burdensome."[21] Pripp and Moretti question whether the legislated right to request life-sustaining treatment creates the corresponding legal obligation to provide such treatment.

> Although it is unlikely that advance directive statutes would be interpreted as creating a positive right to receive any and all treatment, the legislatures that enacted these laws, as well as the individuals who rely on them, most likely believe they are protecting the patient's decision to be kept alive.[22]

Legislation might create a right to ask for treatment but so far, it has not clearly created a corresponding obligation to provide it.

At least 27 states have DNR legislation,[23] the primary focus of which is to facilitate patient refusal of treatment and to protect and promote physician compliance with the request to terminate treatment. Most statutes provide for a presumption of consent to CPR unless a DNR order is made in accordance with the legislation. Most states require the consent of the patient as a pre-requisite to DNR orders. At first glance, this appears to give patients a right to demand CPR; however, some states (New York, Virginia and Georgia) provide an exception to the consent requirement where treatment is futile. Most statutes attempt to restrict futility to the physiological futility formulation.

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[17] Health Care Ethics Consortium of Georgia, *1997 Task Force on Futility Report* (January 1997) 4 (hereinafter referred to as "HCECG Futility Report), online: <http:// www.hcecg.org> (date accessed: 7 May 2002).

[18] National Conference of Commissioners on Uniform State Laws, *Uniform Health Care Decisions Act* (1993) s. 7(f) and commentary, on line: University of Pennsylvania Law School Homepage, <http://www.law.upenn.edu/bll/ulc/fnact99/1990s/uhcda93.htm> (date accessed: 8 May 2002).

[19] W. Pripp and M. Moretti, "Medical Futility: A legal perspective" in M.B. Zucker and H.C. Zucker, eds., *Medical Futility and the evaluation of life-sustaining interventions* (1997) 136 at 146, note 10: Arizona, Idaho, Indiana, Kentucky, Maryland, Minnesota, North Dakota, Oregon, Pennsylvania, South Dakota, Wisconsin.

[20] *Living Wills and Life-Prolonging Procedure Act, Indiana Code* §16-36-4. See also: Manitoba League for Persons with Disabilities, *The Will to Live Template Project: A Discussion among People with Disabilities in Manitoba about the Right to Medical Care* (March 2002).

[21] W. Pripp and M. Moretti, "Medical Futility: A legal perspective" in M.B. Zucker and H.C. Zucker, eds., *Medical Futility and the evaluation of life-sustaining interventions* (1997) 136 at 147.

[22] W. Pripp and M. Moretti, "Medical Futility: A legal perspective" in M.B. Zucker and H.C. Zucker, eds., *Medical Futility and the evaluation of life-sustaining interventions* (1997) 136 at 143.

[23] W. Pripp and M. Moretti, "Medical Futility: A legal perspective" in M.B. Zucker and H.C. Zucker, eds., *Medical Futility and the evaluation of life-sustaining interventions* (1997) 136 at 144.

New York's *Public Health Law*[24] (PHL) offers an interesting example of legislative guidelines to end-of-life decision making and the resolution of disputes. The PHL provides for a presumption of consent to CPR unless there is a DNR order in place. Consent is a pre-requisite to a DNR order and the patient may impose "conditions" which must be satisfied before the DNR will be effective, permitting the patient to provide for a limited or circumstance-specific DNR order.

Physicians can invoke therapeutic privilege to issue DNR orders without consulting the patient where discussing CPR would cause "immediate and severe injury". The PHL sets out guidelines and safeguards which the physician must follow before and after issuing the DNR order including:

- obtaining a second medical opinion before issuing the order;
- ascertaining the patient's wishes as much as possible without discussing CPR;
- recording the reasons for not consulting the patient;
- where possible, obtaining the consent of someone who would be authorized to give consent if the patient were incompetent;
- monitoring the patient's condition and promptly consulting the patient when discussing CPR no longer threatens the patient's well being.

In the case of an incompetent patient without a surrogate decision-maker or where the surrogate does not want to decide, a physician can issue a DNR order without consent when he or she believes "with a reasonable degree of medical certainty, [that] resuscitation would be medically futile". The physician must obtain a second consistent opinion or a court order. "Medically futile" is defined on a physiological basis; that CPR will not restore function or that the patient will suffer an arrest again soon after.

The PHL requires that DNR orders be reviewed at least every 7 days for hospital patients and every 60 days for patients in residential health care facilities.

Hospitals are required to establish mediation systems to resolve disputes and the PHL provides for judicial review of decisions to issue DNR orders. Those challenging a DNR order must show that it is contrary to the patient's wishes or best interests.

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[24] *Public Health Law*, Article 29B, §2962. Information regarding the *Public Health Law* may be found online: Medical Society of the State of New York Homepage, <http://www.mssny.org/members_only/legal/Legal_Guide/DNR.htm> (last modified 22 Nov. 1999).

The United States federal government also has some limited jurisdiction with respect to health care and some federal statutes touch on end-of-life decision making. The federal *Patient Self-Determination Act, 1990*[25] requires that all health care facilities receiving Medicare or Medicaid funds inform patients of their right to accept or refuse medical treatment, any right under state law to make an advance directive, and the facility's policy regarding withholding or withdrawing of life-sustaining treatment.

The Act does not create a right to receive treatment but rather a right to "know" the manner in which decisions are made. Health care facilities must provide the patient with the information necessary to exercise autonomy in health care decision making.[26] This legislation has broad application because most health care facilities receive Medicare or Medicaid funding.

The *Emergency Treatment and Active Labor Act* (EMTALA) was enacted to prevent "patient dumping", a practice in which health care providers refuse to treat patients who receive Medicare or Medicaid funding or who transfer such patients before their condition is stabilized.[27] In *Matter of Baby K*[28] (discussed below), the 4th Circuit Court relied on the EMTALA to compel treatment of a disabled child despite state legislation which permitted withholding treatment on grounds of futility.

American case law has not yet directly addressed the issue of who, as between the health care provider and the patient, has the right to decide whether to withdraw or withhold life-sustaining treatment. Two cases which involved disputes between health care providers and patients were decided on other grounds.

In the case of *In re Helga Wanglie*,[29] the hospital and husband of the patient disagreed about the termination of life support. The hospital applied to replace the husband as the patient's legal guardian but the Court refused to do so as there was no evidence that Mr. Wanglie was not competent to act in his wife's best interest.

In *Matter of Baby K*, the Court held that the EMTALA took precedence over state legislation which authorized the termination of medically or ethically inappropriate treatment. Baby K was born with anencephaly, a condition in which a large part of the brain is missing. Baby K's mother, on religious grounds, insisted on aggressive life-sustaining treatment, contrary to the advice of health care providers who recommended a DNR order and "comfort care". Baby K was eventually weaned from a respirator and transferred to a nursing home although she had to be taken to the emergency department several times to deal with respiratory difficulties.

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[25] *Patient Self-Determination Act of 1990*, §§4206 and 4751 of *Omnibus Reconciliation Act of 1990*, Pub. L. No. 101-508 (Nov. 5, 1990).

[26] L.P. Ulrich, *The Patient Self-Determination Act: Meeting the Challenges in Patient Care* (1999) 185.

[27] W. Pripp and M. Moretti, "Medical Futility: A legal perspective" in M.B. Zucker and H.C. Zucker, eds., *Medical Futility and the evaluation of life-sustaining interventions* (1997) 136 at 142, note 8.

[28] *Matter of Baby K*, 16 F.3d 590 (4th Cir. 1994).

[29] *In re Helga Wanglie*, Fourth Judicial District (Dist. Ct. Probate Ct. Div.) PX-91-283, Minnesota, Hennepin County (July 1991).

The hospital applied for a declaration that it did not have to administer ventilator support to Baby K. The Court refused to grant the order holding that refusing treatment was discrimination on the ground of disability contrary to the EMTALA. While the effect of the decision was to provide treatment, the case was not decided on the basis that the patient has the right to insist on such treatment.

C. CONCLUSION

Unfortunately, we cannot look to either England or the United States for guidance as neither has established clear legislative guidelines governing the withdrawal of life sustaining treatment.

CHAPTER 4

MAKING DECISIONS TO WITHDRAW OR WITHHOLD LIFE-SUSTAINING TREATMENT

A. MEDICAL ETHICS AND THE PHYSICIAN-PATIENT RELATIONSHIP

Health care providers (usually physicians) control access to the publicly funded health care system, and therefore carry great authority and responsibility. While most Canadians trust and respect physicians,[1] as a society we have come to question the exercise of any authority over the individual.

Our history and experience tell us that human beings are not perfect in their exercise of power over others. When one person has the power to exercise a discretion or make a decision which impacts the life of another, there is always the potential for mistakes or even abuse. The inappropriate exercise of power may be conscious and deliberate or quite unintentional but the harm caused is serious regardless.

As a society, safeguarding against the improper exercise of authority in a decision-making process often involves ensuring transparency in that process as well as providing a form of accountability for the decision-maker. Dissatisfaction with the current system of end-of-life decision making may, in part, stem from a lack of transparency and accountability.

As discussed earlier, there are no statutory or common law rules which regulate end-of-life decision-making. The Government of Manitoba, which has primary constitutional authority for health care, has delegated much of its authority for regulating the medical profession and the practice of medicine to the College of Physicians and Surgeons of Manitoba ("the College"). The College has established a *Code of Conduct* .[2] which sets out ethical principles that physicians must follow in medical practice. The College has also established guidelines on various topics (including one for DNR orders).[3] A guideline is not binding, it is a "generally recommended" practice, and establishes a benchmark of acceptable practice. Both the Code of Conduct and Guideline 151 (DNR Orders) support a physician's authority to withhold treatment.

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[1] Canadian Press, "Firefighters, nurses top list of most trusted", *Winnipeg Free Press*, February 25, 2002.

[2] The College of Physicians and Surgeons of Manitoba, *Code of Conduct*, online: <http://www.umanitoba.ca/colleges/cps/Code/index_code.html> (date accessed: 8 May 2002).

[3] The College of Physicians and Surgeons of Manitoba, Guideline 151 (*"Do Not Resuscitate" and Supportive Treatment Orders* (currently under review), online: <http://www.umanitoba.ca/colleges/cps/Guidelines_and_Statements/151.html> (date accessed: 8 May 2002).

Section 1 of the Code of Conduct requires health care providers to "consider first the well being of the patient." Guideline 119 (The Doctor/Patient Relationship) elaborates on this principle and suggests that consideration of the patient's well being requires a balancing of the following principles:

Beneficence	the capacity to have a good effect
Maleficence	the capacity to have a bad effect
Autonomy	the freedom of the individual to self-determine
Justice	the inherent equity given the specific capabilities of the individual

Guideline 119 goes on to describe the ideal doctor/patient relationship as one in which "beneficence is optimized and maleficence is minimized with all decisions being just and respecting patient autonomy." The power to withhold treatments is grounded in this "primary ethical principle".

Section 19 of the Code states that "[t]reatments that offer no *benefit* and serve only to prolong the dying process should not be employed" (emphasis added). Benefit is not defined and may not be capable of precise definition. In cases of conflict, it may be the determination of what constitutes a benefit that is problematic. In terms of including patients in the decision making process, section 19 also requires that health care providers *make an effort* to explain the non-provision of futile treatments to patients and families *when appropriate*. The Code of Conduct does not require patient consent as a pre-requisite to withdrawing treatment. Instead, a health care provider must "ascertain wherever possible and recognize" the patient's wishes about life-sustaining treatment (section 17). The DNR guideline is vague and confusing to the lay person and does not clearly address patient input in decision making. It does not address how disputes should be resolved. The College is currently reviewing this guideline and it will likely be amended in the future.

There are also two "national" professional guidelines which address DNR orders and resolution of disputes. The *Joint Statement on Resuscitative Interventions,*[4] and the *Joint Statement on Preventing and Resolving Ethical Conflicts Involving Health Care Providers and Persons Receiving Care*[5] establish a benchmark of acceptable practice for the profession. The *Joint Statement on Resuscitative Interventions* provides more detailed guidelines than the College's DNR guideline and addresses the need for conflict resolution mechanisms. It states (at page

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[4] Canadian Medical Association, *et al*, "Joint Statement on Resuscitative Interventions" (1995), 153 CMAJ 1652A.

[5] Canadian Healthcare Association, *et al* "Joint Statement on Preventing and Resolving Ethical Conflicts Involving Health Care Providers and Persons Receiving Care" (June 15, 1999), on line: <http://www.canadian-healthcare.org/documents/joint.htm> (date accessed: 7 May 2002).

1652A) that there is no obligation to offer "futile or non-beneficial" treatment but recognizes that these are "controversial concepts when applied to CPR". It considers a treatment to be futile when "it offers no reasonable hope of recovery and improvement or because the person is unable to experience any benefit". Although the Joint Statement's definition appears to be one of physiological futility, the words "reasonable" and "benefit" are often matters of opinion on which reasonable people can, and do, disagree. This suggests some element of qualitative futility as will be discussed below.

All of the existing guidelines respecting decisions to withhold or withdraw treatment are mainly written for and by the medical profession and may not incorporate perspectives of the broader community or other stakeholders. Transparency and accountability in the decision making process might be improved by greater community input to guidelines.

QUESTIONS FOR DISCUSSION

At the end of Chapter 2, we asked what should rules to govern end-of-life decision-making look like. Our next question is:

Question 2: How do we make these new rules?

(a) Who should be involved in creating the rules?

(b) What process or processes should be used?

B. DECIDING ON THE BASIS OF FUTILITY

What does it mean when we say treatment is futile? There is no consensus on the meaning of medical futility, as evidenced by the substantial body of literature on the subject. As Professor Barney Sneiderman points out

> With the exception of the debate over the proposed legalization of physician-assisted suicide and voluntary euthanasia, no topic in the bioethics literature has provoked more soul-searching and controversy than that of medical futility....[6]

Judgments of futility are controversial because they often require a consideration and selection of values. This leads to the question: "Whose values should govern?"

Categorizing a treatment as futile could mean that it will not work (physiological futility) or that it is not worth doing (qualitative futility)[7] If CPR cannot restore pulse or breathing, it is physiologically futile. If CPR will restore pulse and breathing but cannot restore consciousness, it is qualitatively futile.

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[6] B. Sneiderman, "A Do Not Resuscitate Order for an Infant Against Parental Wishes: A Comment on the *Case of Child and Family Services of Central Manitoba* v. *R.L. and S.L.H.*" (1999), 7 Health L.J. 205 at 209.

In general, judgments of physiological futility are considered to require pure clinical judgments and therefore cannot be challenged by the patient. This "privileging" of physiological futility judgments has resulted in the idea that health care providers may withdraw life-sustaining treatment without consent. Only the health care provider can judge whether a treatment is physiologically futile. Once its futility is established, the health care provider is under no duty to provide a treatment. If there is no duty to provide it, then consent is not required.

Qualitative futility judgments, on the other hand, involve decisions about what is worthwhile. Health care providers are expert at deciding whether a particular treatment will achieve a particular outcome. In the current understanding of medical futility, patients are expert at deciding whether that outcome is "good" from their point of view. Two patients in the same situation may arrive at different conclusions about whether the outcome of a proposed treatment is acceptable. For example, a person with a strong belief in the sanctity of life may request life-sustaining treatment while another may want treatment withheld so that they will not linger.

In her book, *When Doctors Say No: The Battleground of Medical Futility*,[8] Susan Rubin challenges the privileging of physiological futility judgments and rejects the presumption that such judgments are "value-free". She suggests that the exercise of clinical judgment will always entail consideration and selection of values at some point.

First, we cannot avoid subjectivity in the analytical process as everyone looks at the world through the "lens" of their own values, experience and attitudes[9]. This lens of experience affects how we perceive and analyze data and even how we frame the question in the first place. In other words, a health care provider's own religious views and other values will affect the manner in which they assess a patient's condition and determine which treatments are appropriate.

Second, medicine is not an exact science and there is much disagreement within the medical profession about diagnoses and treatment. As the medical profession learns more about disease and treatment, earlier views and practices may be rejected.[10]

> Whether a given treatment is "beneficial" may be controversial both scientifically and philosophically. There is much debate within the scientific community over what constitutes an

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[7] See definition of futility at page 3.

[8] S.B. Rubin, *When Doctors Say No: The Battleground of Medical Futility* (1998).

[9] S.B. Rubin, *When Doctors Say No: The Battleground of Medical Futility* (1998) 96-101.

[10] S.B. Rubin, *When Doctors Say No: The Battleground of Medical Futility* (1998) 60 and 110.

> agreed-upon standard or range of goals for a particular disease and the alternative treatment options to be considered. Standards of practice are frequently subject to question as the outcome data are often not available or inconclusive. Therefore, much uncertainty exists about the prognosis for certain diseases and the projected efficacy of alternative treatments. Professional societies' statements may offer conflicting views of what constitutes "futile treatment" which physicians are "under no obligation" to offer. In addition, there may be great variation in how individual clinicians within the same specialty assess beneficiality and communicate their assessments to patients or their surrogates.[11]

Determining the appropriate measure of success in order to assess the effectiveness of treatment can be problematic and may also require a selection of values. If a treatment has failed in the last 99/100 cases, it may be rejected even though the patient who survives would likely consider the treatment worth doing.[12]

> The statistical cutoff point chosen ... as the threshold for determining futility is relative to opinion. Why not, three percent, or five percent (as is customarily adopted in scientific research)? No matter what point is selected, there is always a potential survivor not predicted to survive, prompting the public and the courts to spend vast quantities of scarce resources to avoid the possibility of that survivor expiring. Even if there was agreement on a statistical cutoff point for determining futility, physicians are often highly unreliable in estimating the likelihood of success of a therapeutic intervention. Even in theory, statistical inferences about what might happen to groups of patients do not permit accurate predictions of what might happen to the next patient.[13]

Third, judgments of physiological futility will require reference to and selection of values when identifying the appropriate goals of treatment. When we say CPR will not work, we must first consider what it is that we are trying to achieve. If the desired outcome is eventual discharge from the hospital, CPR may be futile. If the goal is to restore some degree of function or to extend the patient's life for a short time, then CPR may not be futile. Whether or not a treatment is "futile" depends on the goal selected. The selection of goals requires a value judgment.[14]

The line between physiological and qualitative futility can be very fine and an opinion about the qualitative futility of a particular treatment may "creep in" to the determination of its physiological futility. In *Sawatsky,* the physician's evidence in support of the DNR order demonstrated a mingling of physiological and qualitative futility. The physician opined that the CPR *probably* would not work (physiological futility) but also that, even if it did work, it would not be worthwhile (qualitative futility) because of the harm it would *probably* cause.

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[11] Health Care Ethics Consortium of Georgia, *1997 Task Force on Futility Report* (January 1997) 2 (hereinafter referred to as "HCECG Futility Report), online: <http:// www.hcecg.org> (date accessed: 7 May 2002).

[12] S.B. Rubin, *When Doctors Say No: The Battleground of Medical Futility* (1998) 61-62.

[13] L. Olmsted, "Medical Futility", on line: <http://www.wramc.amedd.army.mil/departments/Judge/futility.htm> (date accessed: 7 May 2002).

[14] S.B. Rubin, *When Doctors Say No: The Battleground of Medical Futility* (1998) 88 and 101-102.

> ... given Mr. Sawatsky's health condition, it is improbable that, even if initiated cardiopulmonary resuscitation would succeed. If cardiopulmonary resuscitation did succeed, it is very probable that the most it would serve is to keep Mr. Sawatsky on a life-support system. In the unlikely event that Mr. Sawatsky was successfully removed from life-support, particularly considering his current level of brain impairment, it is very likely that he would be left with additional brain damage, and in a persistent vegetative state.[15]

Olmsted suggests that futility itself "generally fails to provide an ethically coherent ground for limiting life-sustaining treatment"[16] and that the approach to end-of-life decision making should be based upon the interests of the patient.

Rubin not only argues that decisions to withdraw treatment should not be based on futility but also that futility should not be used to justify what she calls "physician unilateral decision making". She advocates for more meaningful patient participation in end-of-life decisions.

> I have contended that physician unilateral decision making is an excessive and unnecessarily harsh solution to the problem of futility. The practice of physician unilateral decision making damages the trust that is essential to a successful therapeutic relationship between patients and their care providers. Moreover, physician unilateral decision making misconstrues the very grounding of the physician-patient relationship. At its worst, physician unilateral decision making constitutes an unjustified violation of patient autonomy, a return to the oldest form of unjustified paternalism, an unjustified generalization of physician expertise, a breach of the contract between the medical profession and society, and an unwarranted exercise of power.[17]

1. Why Do Patients Request Futile Treatment?

There are many reasons why a patient might request life-sustaining treatment which is futile. The patient may want to live longer in order to make arrangements or say good-bye to family. Some believe that a miracle may occur. The patient's deeply held moral or religious belief in the sanctity of life may require that he or she do everything possible to prolong life.

Sometimes, the demand for treatment comes from unrealistic expectations about the potential outcome. An Australian study[18] of patient attitudes to CPR showed a generally poor knowledge of the success rate of CPR. The study suggested that the cause of unrealistic expectations was inaccurate information from television, books, magazines and public information which tends to emphasize the benefits of CPR and not the risks. Once patients received accurate information about CPR, its success rate and the side effects, they changed their minds about wanting CPR.

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[15] Affidavit of Dr. Boutscha, quoted in *Do Not Resuscitate Orders and the Law in Canada -- Patient's Rights* (October 2000) 27 (a paper prepared for the Manitoba League of Persons with Disabilities by Sherri Walsh, LL.B.).

[16] L. Olmsted, "Medical Futility", on line: <http://www.wramc.amedd.army.mil/departments/Judge/futility.htm> (date accessed: 7 May 2002).

[17] S.B. Rubin, *When Doctors Say No: The Battleground of Medical Futility* (1998) 117.

[18] I. Kerridge, S.A. Pearson, I. Rolfe, M. Lowe and J. McPhee, "Impact of Written Information on Knowledge and Preferences for Cardiopulmonary Resuscitation" (1999) 171 Med. J. Aust. 239-242.

Fear, guilt, denial, grief, anger and so many other emotions that naturally accompany a life-threatening condition or crisis will affect a patient's desire for treatment. For the family of the patient, making a decision to withdraw or withhold care can seem tantamount to causing the death of their child, parent or sibling. A difficult family dynamic may further complicate decision-making when there are unresolved emotional issues or when family members cannot agree.

In a recent newspaper article on palliative care, Margaret Clarke, executive director of Hospice and Palliative Care Manitoba, is quoted as saying "We have been conditioned to believe that with all the cures and treatments that we can live forever." Canadians, she suggests, are "reluctant to admit that their lives will end and try to keep death at arm's length for as long as possible".[19]

Health care providers may also find it difficult to discuss death with patients, particularly patients who are young or who are unknown to them. A study of 10 family physicians[20] found that raising the issue of DNR orders was challenging for physicians. Their own uneasiness about death and fear of damaging their patient's trust was a barrier to communication. Additional pressure is created when there is conflict within the patient's family.

> Our study echoes a number of themes in the literature. Discomfort with the topic of death, time constraints, discontinuity of physician care between outpatient and hospital settings, and concern about patient and family reactions have been cited as barriers to physician-initiated discussions about advance directives....attending physicians' and residents' comfort with discussing death, experiences with death and dying, ability to "let go" of the patient and personal knowledge of the patient influenced their approach to code-status decision-making.[21]

In some cultures and religions, a belief in the sanctity of life and an obligation to do everything possible to maintain life may prompt requests for life-sustaining treatment. Fears of racial or cultural discrimination may also affect how people react to a proposal to withdraw or withhold treatment. For members of historically disadvantaged groups, distrust of those in authority may contribute to demands for life-sustaining treatment.

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[19] P. Samyn, "Compassionate Journey", *Winnipeg Free Press*, Thursday, February 28, 2002, A10.

[20] B. Calam, S. Far, R. Andrew, "Discussions of 'code status' on a family practice teaching ward: What barriers do family physicians face?" (2000), 163(10) C.M.A.J. 1255.

[21] B. Calam, S. Far, R. Andrew, "Discussions of 'code status' on a family practice teaching ward: What barriers do family physicians face?" (2000), 163(10) C.M.A.J. 1255 at 1258.

> African Americans who enter the primary care setting are three times more likely than Caucasians to desire more end-of-life care. This may result in part from more strongly held religious beliefs and faith in miracles, but there also appears to be a strong expectation of inadequate care because of race.[22]

2. Futility and the Disabled

In *Lavallee*, the Manitoba Court of Appeal decided that prolonging the life of a patient in a permanent vegetative state was not worthwhile, a position we see repeated by the House of Lords in *Bland* and by the Supreme Court of Canada in *Rodriguez*. In *Rodriguez*, the Supreme Court recognized sanctity of life to be a principle of fundamental justice but also recognized that it was not an absolute. The Court found that diminished quality of life may be an exception to the principle of sanctity of life.

Quality of life is not a concept which can be defined with precision. It varies greatly from person to person and may change for any given person. While an able bodied person might think they would have significantly diminished quality of life if they were to become disabled, they might change that view if they do become disabled and are still able to enjoy life.

Advocates for the disabled challenge decision making on the basis of "quality of life" considerations. Past experience has shown them the personal beliefs of physicians and decision-makers about their quality of life will have a negative or discriminatory effect on the disabled. Chief Justice Lamer (as he then was) commented on this "devaluation" of the lives of the disabled in his dissent to *Rodriguez*,

> Sadly, increasingly less value appears to be placed in our society on the lives of those who, for reasons of illness, age or disability, can no longer control the use of their bodies.[23]

Health care providers who project their own values and attitudes about quality of life into the decision making process may withdraw or withhold treatment prematurely. Thoughts of "I would not want to live like that" may turn to "You must not want to live like that" which may, in turn result in a decision that "you should not live". While some may agree with Professor Sneiderman that "it is pointless, dehumanizing, and a waste of resources to maintain the life of a PVS [permanent vegetative state] patient"[24] or that it is appropriate to withhold life sustaining treatment from a person in the end stages of a terminal illness, these are by no means universal views. Bioethicist Dr. Charles Weijer has challenged the assertion that it is appropriate to withdraw life-support from a patient in a permanent vegetative state suggesting that such a decision does not depend on whether treatment will work but rather on deciding what kind of life is worth preserving.[25]

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[22] M.F. Morrison and S.Gelbach Demichele, "How culture and religion affect attitudes toward medical futility", in M.B. Zucker and H.C. Zucker, eds., *Medical Futility and the evaluation of life-sustaining interventions* (1997) 71 at 78.

[23] *Rodriguez* v. *British Columbia (Attorney General)*, [1993] 3 S.C.R. 519 at 565.

[24] B. Sneiderman, "A Do Not Resuscitate Order for an Infant Against Parental Wishes: A Comment on the *Case of Child and Family Services of Central Manitoba* v. *R.L. and S.L.H.*" (1999), 7 Health L.J. 205 at 211.

In its paper entitled, *Our Last Rights: Do Not Resuscitate Orders and People with Disabilities*,[26] the Manitoba League for Persons with Disabilities gives examples of the impact of negative attitudes and stereotypes about the value and quality of life of the disabled on medical decision making. In essence, discriminatory attitudes and beliefs about the disabled result in treatment decisions that, implicitly, say that the lives of disabled people are not worth preserving.

The benefits of a transparent decision making process and a dispute resolution system may become particularly important for patients who are historically disadvantaged in society. Reducing the exercise of individual discretion would also reduce vulnerability to decision makers with discriminatory attitudes and beliefs.

3. Futility and the Elderly

Age Concern, an advocacy organization for the elderly, has raised the alarm about age discrimination by the National Health Service in England. Patients reported that they were told that they were too old for treatment, were not told about particular treatments, received a lower quality of care or were assigned a low priority.[27]

The elderly in England have expressed concerns that they are being left to die with little regard to their potential for an enjoyable or meaningful (to the patient) life. Most people not only want to make the most of their remaining years but want to maximize the number of remaining years as well.

Inadequate health care for the elderly is already an issue in Canada. With our aging population and an already over-taxed health care system, examples of inappropriate or premature decisions to withhold or withdraw care may increase.

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[25] C. Weijer, "Cardiopulmonary Resuscitation for Patients in a Persistent Vegetative State: Futile or Acceptable?" (1998), 158 CMAJ: 491 at 493.

[26] R. Wiebe, *Our Last Rights: Do Not Resuscitate (DNR) Orders and People with Disabilities* (MPLD, 2000) 78-86.

[27] Age Concern, online: <http://www.ageconcern.org.uk/> (date accessed: 9 May 2002).

4. Religion, Culture and Race

Canada's population comprises a broad diversity of culture, religion and language. There is a wide range of views regarding end-of-life care and decision making between and within cultural and religious groups.

Charles Weijer argues that it is unethical to withdraw or withhold life-sustaining treatment from patients whose religious views, such as Orthodox Judaism, Protestant Fundamentalism and conservative Catholicism, include "a deeply rooted belief in the sanctity of life, a belief in the God-given sacredness of human life". In the case of Orthodox Judaism, there may be an obligation to "seek out and accept life-prolonging treatment."[28]

> Even though patients in a PVS lack the capacity for suffering, they must be treated with dignity. Is the provision of CPR to patients in a PVS an indignity? Dignity is sensitive to the particulars of the situation. For example, kneeling is an indignity if I require it of my research assistant in my presence; it is not an indignity if it is required as part of his religious observances. Similarly, CPR in cases of PVS may indeed be an indignity to those who do not believe in the sanctity of life. Yet it may not be an indignity to those who in receiving treatment are fulfilling an obligation to their God. Thus, a valid evaluation of dignity must be sensitive to the cultural and religious context of the patient, and physicians must be careful not to project their own culturally biased assessment on patients of different backgrounds.[29]

"Cultural and religious differences between the patient and the medical team are an underappreciated barrier to negotiating a sensitive and dignified process of dying for the patient."[30] For example, in some Aboriginal and Asian cultures, discussing death *with the patient* is believed to hasten death. It is therefore appropriate for the *patient's family* to receive information and make decisions in order to protect the patient from harm.

> Direct, unmediated communication of "bad news" involving terminal prognosis or risks of impending death may violate some individual's and community's values. Cultural and spiritual traditions, including those of Navajo people in the United States and Dene people in Canada, assert that speaking explicitly about terminal illness and death may hasten death. Some families may therefore ask to be present to mediate the communication of bad news and support the family.[31]

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[28] C. Weijer, "Cardiopulmonary Resuscitation for Patients in a Persistent Vegetative State: Futile or Acceptable?" (1998), 158 CMAJ 491 at 492.

[29] C. Weijer, "Cardiopulmonary Resuscitation for Patients in a Persistent Vegetative State: Futile or Acceptable?" (1998), 158 CMAJ 491 at 492.

[30] M.F. Morrison and S.Gelbach Demichele, "How culture and religion affect attitudes toward medical futility", in M.B. Zucker and H.C. Zucker, eds., *Medical Futility and the evaluation of life-sustaining interventions* (1997) 71 at 71.

[31] J. Ellerby, J. McKenzie, S. McKay, G. Gariepy, J. Kaufert, "Bioethics for Clinicians: 18 Aboriginal Cultures" (2000), 163 C.M.A.J. 846 at 847.

The Euro-Canadian focus on full disclosure and individual autonomy will conflict with some cultural traditions and cause harm.

> In times of crisis and when facing one's own mortality, religious and familial/cultural values are sources of strength and comfort. Recently, authors have disagreed about whether the Western emphasis on autonomy and full disclosure is respectful of dying patients with different cultural traditions. In the Asian, Hispanic, and other traditions, autonomy must be balanced against such values as family and community support and compassion. Full disclosure may be at variance with cultural beliefs about hope and wellness, and autonomous decision making may counter family-centered values.... The patient's values determine whether it is beneficial or burdensome to be fully informed.[32]

Thus it is not just the decisions themselves which may be culturally or spiritually inappropriate for the patient, but the process of arriving at the decision which may also offend cultural and religious beliefs.

Our health care system may not reflect Canada's cultural or religious diversity. Mainstream medicine has been slow to incorporate diverse cultural practices. One example of conflict between a generally accepted medical concept and the cultural and religious beliefs of some Canadians may be found in the medical definition of death. At common law, death is defined as the "irreversible cessation of cardiopulmonary functioning"[33] (heartbeat and breathing). It is possible to maintain heart and lung function artificially so that a patient who has no brain function would still be legally alive. The medical profession developed the concept of "brain death" which has now been accepted as the legal standard of death in most US states and in Manitoba.[34] Even without legislative acceptance, physicians in other provinces follow the brain death standard pursuant to Canadian Medical Association guidelines and not the common law definition of death.[35]

While the brain death standard may be appropriate for many, it will offend people whose culture or religion includes a belief in the absolute sanctity of life and the obligation to preserve life at all costs. Accepting the brain death standard is not simply a medical decision but is a social and moral decision which reflects the beliefs of the dominant culture.

> The advent of neurologic or brain death criteria to establish the death of a person was a significant departure from the traditional way of defining death and remains ethically challenging. However,

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[32] M.F. Morrison and S.Gelbach Demichele, "How culture and religion affect attitudes toward medical futility", in M.B. Zucker and H.C. Zucker, eds., *Medical Futility and the evaluation of life-sustaining interventions* (1997) 71 at 71.

[33] B. Sneiderman, J.C. Irvine and P.H. Osborne, *Canadian Medical Law: An Introduction for Physicians, Nurses and other Health Care Professionals* (2nd ed., 1995) 327.

[34] *The Vital Statistics Act*, C.C.S.M. c. V60, s. 2.

[35] B. Sneiderman, J.C. Irvine and P.H. Osborne, *Canadian Medical Law: An Introduction for Physicians, Nurses and other Health Care Professionals* (2nd ed., 1995) 327.

> regardless of which criteria are used, agreement about when death occurs is not simply an agreement about medical or biological criteria for death but is also a "social formulation.[36]

New Jersey has responded to this concern by providing for a religious exception to the brain death standard. New York has, by regulation, encouraged recognition of religious views in the legal determination of death. It is therefore possible, in "fill[ing] the gap between old law and new medicine"[37] to provide a legislative response which allows for accommodation of religious or cultural diversity.

QUESTIONS FOR DISCUSSION

Earlier in this paper, we asked what form rules should take and what process should be followed to create them. Now we ask:

Question 3: What should the rules be?

(a) **Should health care providers be required to obtain a patient's consent before withholding or withdrawing treatment?**

(b) **If yes, should there be limits to the requirement to obtain consent? What should the limits be?**

(c) **If consent is not required, who should decide to withhold or withdraw treatment?**

(d) **What criteria should be followed in making such decisions?**

(e) **If consent is not required, how can patients' wishes and interests be honoured and protected?**

(f) **If decisions to withhold or withdraw treatment are based on "futility", should a legal definition of futility be established?**

Question 4: How should disputes be resolved?

(a) **What should a dispute resolution process look like? Should it be informal or formal? Mediation, arbitration or court application?**

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[36] N. M. Lazar, S. Shemie, G.C. Webster, B.M. Dickens, *Bioethics for clinicians: 24 Brain death* (2001) 164(6) CMAJ 833-836.

[37] *Airedale NHS Trust* v. *Bland*, [1993] 1 All E.R. 821 at 888 (H.L.) per Lord Mustill.

(b) Who should administer the dispute resolution process - health care providers or an independent agency?

(c) Who should be responsible for funding and administering the process?

C. DNR POLICIES IN MANITOBA

In 1997, the Manitoba Government delegated some authority for health care policy, planning and service delivery to 12 Regional Health Authorities (RHA).[38] Together, these regional health authorities manage Manitoba's 78 hospitals, 116 personal care homes and 28 community health centres/clinics.[39]

In 2000, the Manitoba League for Persons with Disabilities (MPLD) surveyed Manitoba RHAs and a sampling of 26 rural and urban hospitals and long term care facilities with respect to their DNR order policies and practices.[40] The responses show that there is inconsistency across Manitoba in DNR order policies. Some RHAs and facilities did not have DNR order policies or were developing policies. For the RHAs and facilities which did have policies, there were significant differences in the policies, particularly within the Winnipeg Regional Health Authority.

Three Manitoba RHAs had a policy governing the placement of DNR orders although each was somewhat different. The remaining RHAs had no policy or were developing policy. Three regions ((Burntwood, Brandon, Dauphin) required patient's consent for DNR orders while one region encouraged consent (Winnipeg), another left it up to each institution (Parkland) and the others were developing policy.

Policies which did not require consent to DNR orders typically did not impose an obligation to advise the patient of the DNR order and had no dispute resolution process in place to resolve disagreements.

The WRHA encourages facilities to obtain consent for and advise patients of DNR orders. There are differences in policy between various health care facilities in the WHRA. For example, the Health Sciences Centre and the St. Boniface Hospitals require patient consent as a pre-requisite to DNR orders, Seven Oaks recommends consent, Victoria General Hospital requires consultation and Riverview Health Centre has an automatic DNR order placed upon admission.

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[38] *The Regional Health Authorities Act*, C.C.S.M. c. R34.

[39] Manitoba Health, *Region Index for Regional Health Authorities*, (December 15, 1999), online: <http://www.gov.mb.ca/health/rha/commreg.pdf> (date accessed: 8 May 2002).

[40] R. Wiebe, *Our Last Rights: Do Not Resuscitate (DNR) Orders and People with Disabilities* (MPLD, 2000) 47-64.

Manitobans may not realize that there are policy differences between various health care institutions. This gives rise to the following questions:

QUESTIONS FOR DISCUSSION

Question 5: Should health care facilities' policies governing withdrawing and withholding of care be mandatory?

(a) Should policies be consistent or have certain mandatory requirements?

(b) Should policies be determined
  (I) at the provincial level (for all institutions)?
  (ii) at the regional level (RHA)?
  (iii) at the institutional level?

(c) Should there be different types of policies depending upon the nature of the health care facility?

(d) Are automatic DNR policies appropriate? In what circumstances or for which kinds of facilities?

The Commission also invites health care providers (institutions and individuals) to provide information about their policies and practices governing the withdrawing and withholding of treatment.

D. ECONOMIC CONSIDERATIONS: SHOULD THEY BE RELEVANT?

Should scarcity of resources be a consideration in decisions to withhold or withdraw life-sustaining treatment? If a requested treatment is truly futile, should it be administered if it is inexpensive? Should effective treatments be provided regardless of the cost (assuming the treatment is reasonably accessible)? Even if there was general agreement that scarcity of resources should not be relevant to end-of-life decision making, the current debate about the continued viability of the health care system leads to the perception that a consideration of resources will factor into decisions to withdraw care. Thus, we must identify and confront the economic issues in this discussion.

In its position paper entitled *Establishing "Medically Required" and Core Services,*[41] the British Columbia Medical Association (BCMA) considers the development of a "priority preference list of services." British Columbia's health care legislation, like Manitoba's, provides that "medically required" health care services are covered by the provincial health insurance plan but does not define what those services are. The BCMA suggests that

> A decision to restrict the scope of services covered under health insurance must ultimately be a policy choice implemented by government, based on economic factors, public opinion and medical input. This decision is one of economic rationing, not of medical necessity.[42]

Publicly funded health care systems around the world are facing the challenge of providing universal health care services and are responding by restricting the scope of available services. In England, the Court of Appeal declined to interfere with a health care authority's decision not to fund a third round of cancer treatment for a young patient. In that case, the treatment was very expensive and the chance of success was small.

> I have no doubt that in a perfect world any treatment which a patient, or a patient's family, sought would be provided if doctors were willing to give it, no matter how much it cost, particularly when a life was potentially at stake. It would however, in my view, be shutting one's eyes to the real world if the court were to proceed on the basis that we do live in such a world. It is common knowledge that health authorities of all kinds are constantly pressed to make ends meet.... Difficult and agonising judgments have to be made as to how a limited budget is best allocated to the maximum advantage of the maximum number of patients. That is not a judgment which the court can make.[43]

QUESTIONS FOR DISCUSSION

Question 6: Should economic consideration be relevant? If so, how?

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[41] British Columbia Medical Association, "Establishing 'Medically Required' and Core Services" (April 2000), online: <http://www.bcma.org/IssuesPolicy/IssueBackgrounders/medicallyrequired.asp> (date accessed: 8 May 2002).

[42] British Columbia Medical Association, "Establishing 'Medically Required' and Core Services" (April 2000) para. 1, online: <http://www.bcma.org/IssuesPolicy/IssueBackgrounders/medicallyrequired.asp> (date accessed: 8 May 2002).

[43] *R.* v. *Cambridge Health Authority, Ex. p.B,* [1995] 2 All E.R. 129 at 137 (C.A.).

CHAPTER 5

ISSUES FOR DISCUSSION

Most people want to die with dignity, a concept which implies a measure of control over the dying process. To be subject to the control of another person at such a critical time may cause distress and give rise to concerns that we will be "let go" when we are not ready or in a way that is inconsistent with our philosophical or spiritual beliefs.

While guidelines of the medical profession *recommend* that patients be consulted about decisions to withhold or withdraw treatment, there is no legal obligation to do so. Susan Rubin suggests consultation without the potential to influence the outcome is inappropriate.

> The opportunity to participate must be genuine and meaningful. Merely disclosing the intent to deny treatment on the grounds of futility, putting patients on notice, or referencing professional position statements or institutional policies is insufficient if physicians ultimately have the power to make and implement treatment decisions on the basis of their judgments of futility. In such an approach concessions to patients constitute only lip service, not actual opportunities to influence, much less control , the decision making process.[1]

It is perhaps this lack of control over what will happen which is the greatest source of dissatisfaction for patients and families affected by decisions to withhold treatment.

On the other hand, giving patients greater autonomy may infringe the health care provider's professional autonomy and integrity. Since resolution of this conflict requires a balancing of the rights and obligations of patients and health care providers, we must engage in a broad based social dialogue and seek a consensus on the scope of patient and physician autonomy in decisions to withdraw or withhold treatment.

The questions raised throughout the paper are reproduced here for ease of reference:

Question 1: What should be the nature or form of legal rules governing decisions to withdraw and withhold life-sustaining treatment?

For example:
(a) legislative guidelines (statutes or regulations to existing or new legislation)?
(b) amendments to existing professional guidelines?
(c) other?

Question 2: How do we make these new rules?

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[1] S.B. Rubin, *When Doctors Say No: The Battleground of Medical Futility* (1998) 117.

(a) Who should be involved in creating the rules?

(b) What process or processes should be used?

Question 3: What should the rules be?

(a) Should health care providers be required to obtain a patient's consent before withholding or withdrawing treatment?

(b) If yes, should there be limits to the requirement to obtain consent? What should the limits be?

(c) If consent is not required, who should decide to withhold or withdraw treatment?

(d) What criteria should be followed in making such decisions?

(e) If consent is not required, how can patients' wishes and interests be honoured and protected?

(f) If decisions to withhold or withdraw treatment are based on "futility", should a legal definition of futility be established?

Question 4: How should disputes be resolved?

(a) What should a dispute resolution process look like? Should it be informal or formal? Mediation, arbitration or court application?

(b) Who should administer the dispute resolution process - health care providers or an independent agency?

(c) Who should be responsible for funding and administering the process?

Question 5: Should health care facilities' policies governing withdrawing and withholding of care be mandatory?

(a) Should policies be consistent or have certain mandatory requirements?

(b) Should policies be determined
    (I) at the provincial level (for all institutions)?
    (ii) at the regional level (RHA)?
    (iii) at the institutional level?

(c) Should there be different types of policies depending upon the nature of the health care facility?

(d) Are automatic DNR policies appropriate? In what circumstances or for which kinds of facilities?

The Commission also invites health care providers (institutions and individuals) to provide information about their policies and practices governing the withdrawing and withholding of treatment.

Question 6: Should economic consideration be relevant? If so, how?

The Commission also invites health care providers (institutions and institutions) to provide information about their policies and practices governing the withdrawing and withholding of treatment.

APPENDIX B

LIST OF PERSONS, ASSOCIATIONS AND INSTITUTIONS WHO RESPONDED TO THE DISCUSSION PAPER

Alzheimer Society Manitoba

Dr. Elizabeth Boutscha, Chief Medical Officer, Riverview Health Centre

Catholic Health Association of Manitoba

College of Physicians and Surgeons of Manitoba

Deer Lodge Centre, Ethics Committee

Dr. Bernard De Leo, retired physician, Sun City Center, Florida

Theresa Ducharme, People in Equal Participation, Inc.

Mariliyn Dupré, Social Worker, Winnipeg

Dan Evans, Woodlands, Manitoba

Dr. Perry Gray, Chief Medical Officer, Critical Care Site Manager, Health Sciences Centre

Health Sciences Centre, Clinical Ethics Service

Ian Anderson Program, Continuing Education for Physicians in End-of-Life Care, University of Toronto

Shelley Irvine-Day, Speech Language Pathologist, Winnipeg

Don Logan, Winnipeg

Manitoba Medical Association

Manitoba League of Persons with Disabilities Inc.

Public Trustee of Manitoba

Riverview Health Centre

St.Boniface General Hospital, Health Care Ethics

Victoria General Hospital

Winnipeg Regional Health Authority, Critical Care Program

Winnipeg Regional Health Authority, Medical Advisory Committee

Winnipeg Regional Health Authority, Standards Committee

LIST OF PERSONS/ORGANIZATIONS/AGENCIES WHO RECEIVED COPIES OF THE DISCUSSION PAPER

Regional Health Authority

Brandon Regional Health Authority Inc.

Burntwood Regional Health Authority

Regional Health Authority Central Manitoba Inc.

Churchill Regional Health Authority Inc.

Interlake Regional Health Authority Inc.

Marquette Regional Health Authority Inc.

Nor-Man Regional Health Authority Inc.

North Eastman Health Association Inc.

Parkland Regional Health Authority Inc.

South Eastman Health

South Westman Regional Health Authority Inc.

Legal Counsel
Winnipeg Regional Health Authority

General Counsel and Corporate Secretary

Winnipeg Regional Health Authority

Vice President of Institutional Care
Winnipeg Regional Health Authority

Associations

Registrar, College of Physicians and Surgeons

Legal Counsel, College of Physicians and Surgeons

Manitoba Medical Association

Alzheimer Society Manitoba

Assembly of Manitoba Chiefs

Mother of Red Nations

Women's Legal Education and Action Fund

Manitoba League of Persons with Disabilities Inc.

Hospitals and Medical Centres

Ethics Services, Health Sciences Centre

Ethics Committee, Concordia Hospital

Ethics Committee, Health Sciences Centre

Chief Medical Officer, Deer Lodge Centre

Ethics Committee, Misericordia Health Centre

Ethics Committee, St.Boniface General Hospital

Ethics Committee, Victoria General Hospital

Ethics Committee. Riverview Health Centre

Ethics Committee, Grace General Hospital

Ethics Committee, Seven Oaks General Hospital

Ethics Committee, Cancer Care Manitoba

Chief Medical Officer, Deer Lodge Centre

Bethania Mennonite Personal Care Home

Calvary Place Personal Care Home

Centre Tache Centre

Concordia Place

Deer Lodge Centre

Donwood Manor Personal Care Home

Fred Douglas Lodge

Golden Links Lodge

Golden West Centennial Lodge

Holy Family Nursing Home

Lions Personal Care Centre

Luther Home

Meadowood Manor

Misericordia Health Centre

Park Manor Personal Care Home Inc.

Riverview Health Centre

St. Joseph's Residence Inc.

The Convalescent Home of Winnipeg

Middlechurch Home of Winnipeg

The Sharon Home Inc.

West Park Manor

Beacon Hill Lodge

Charleswood Care Centre

Extendicare/Oakview Place

Extendicare/Tuxedo Villa

Fort Garry Care Centre

Golden Door Geriatric Centre

Heritage Lodge

Kildonan Personal Care Centre

Parkview Place

Poseidon Care

River East Personal Care Home Ltd.

St. Norbert Nursing Home

Vista Park Lodge

Judiciary

Chief Justice of Manitoba, Manitoba Court of Appeal

Chief Justice, Court of Queen's Bench

Associate Chief Justice, Court of Queen's Bench (General Division)

Associate Chief Justice, Court of Queen's Bench (Family Division)

Manitoba Executive Council

Premier of Manitoba

Minister of Transportation and Government Services

Minister of Labour & Immigration

Minister of Health

Minister of Intergovernmental Affairs

Minister of Conservation

Minister of Agriculture & Food

Minister of Justice & Attorney General

Minister of Aboriginal and Northern Affairs

Minister of Advanced Education

Minister of Industry, Trade & Mines

Minister of Family Services & Housing

Minister of Education, Training & Youth

Minister of Culture, heritage & Tourism

Minister of Finance

Minister of Consumer and Corporate Affairs

Department of Justice

Deputy Minister of Justice and Deputy Attorney General

Director, Civil Legal Services, Civil Justice Division

Public Trustee of Manitoba

Other Governmental Departments

Council on Aging

Manitoba Seniors Directorate

Manitoba Health, Legislative Unit

Office of the Vulnerable Persons' Commissioner

Public Interest Law Centre, Legal Aid Manitoba

Individuals

Sherri Walsh, practising lawyer, Winnipeg

Harvey Secter, Dean, Faculty of Law

Prof. Barney Sneiderman, Faculty of Law

Dr. Bernard C. DeLeo, Sun City Center, Florida

Iris C. Allen, Civil Legal Services, Manitoba Department of Justice

Patricia G. Ritchie, Q.C., Winnipeg

Mr. Arthur Schafer, Department of Philosophy, University of Manitoba

Dr. Michel Silberfeld, Baycrest Centre for Geriatric Care, Toronto

Prof. Edward W. Keyserlink, Biomedical Ethics Unit, McGill University

Dr. Peter Singer, Centre for Bioethics, University of Toronto

Religious organizations

Anglican Church of Canada

Hindu Society of Manitoba

Lutheran Church-Canada

Mennonite Church Manitoba

Salvation Army

Sikh Society of Manitoba

United Church of Canada

Archdiocese of St.Boniface

Archdiocese of Winnipeg

Ukrainian Catholic Archeparchy of Winnipeg

Canadian Jewish Congress

Law Reform Commissions (Canada)

Law Commission of Canada

Law Reform Commission of Nova Scotia

Alberta Law Reform Institute

British Columbia Law Institute

Legislative Services Branch, New Brunswick Department of Justice

Law Reform Commission of Saskatchewan

On request

Colleen Watters

Marion Pringle, Regional Director, Central Park Lodges

M. Young Research and Consulting, Winnipeg

Suzanne Dunwoody, Administrative Assistant, St.Boniface General Hospital

Jackie Jeal, Salvation Army Ethics Centre

Theresa Ducharme, Winnipeg

Ms Jeannette Edwards, Winnipeg Regional Health Authority

Irene Hamilton, Assistant Deputy Minister-Courts, Manitoba Department of Justice

Alwine Willoughby, Salem Home Inc., Winkler, MB

Joanna Knowlton, Public Trustee Office, Winnipeg

Lorne Charbonneau, VP Health Services, Interlake Regional Health Authority

Reg Toews, Chief Executive Officer. South Eastman Health

Wendy Schettler, Program Director, Alzheimer Society of Manitoba

K. T. Riese, M.D., Winnipeg, MB

Penney Lewis, Lecturer in Law, School of Law and Centre of Medical Law and Ethics, King's College, London, England

Candace Myers, Manitoba Speech and Hearing Association

Frank Pisa, Manitoba Speech and Hearing Association

Dr. Jaroslaw Barwinsky, Professor Emeritus, Department of Surgery, Faculty of Medicine, University of Manitoba

Janine Ennis, Department of Communication Disorder, Faculty of Medicine, University of Manitoba

Margaret Clarke, Executive Director, Hospice and Palliative Care Manitoba

Rita Mymko, Lion's Club of Winnipeg, Housing Centres

Martina Munden, Health Law Institute, Dalhousie University

Rosemary Hnatiuk, practising lawyer, Fisher Branch, MB

Helen Babiniec, President, Ukrainian Catholic Women's League

Dr. Laura Hawryluck, Joint Centre for Bioethics, Continuing Education, Faculty of Medicine, University of Toronto

Shelly Irvine-Day, Profession Leader, Department of Communication Disorders, Deer Lodge Centre

Kristine Svendson, Central Manitoba Regional Health Authority

Dr. Bogan Paunovic, Critical Care Program, Health Sciences Centre

Alison Baird, Speech Pathologist, Winnipeg

Dr. Andrej Hnatov, Winnipeg

Pat Trozzo, Cancer Care Manitoba

Gertie Oliveira, North Eastman Health Association Inc.

Francis St. Hilaire, Great West Life, Law Department

Evelyn Sabourin, Foyer Valade

Kim Hansen, Social Worker, St.Boniface Hospital

Marie Edwards, University of Manitoba, Faculty of Nursing

Dr. Ryan Zarychanski, Faculty of Medicine, University of Manitoba, Department of Internal Medicine

Dorothy Lachance, Coordinator or Pastoral Services, Archdiocese of Winnipeg

Dan Lapuk, CNS, Riverview Health Centre

Council of Canadians with Disabilities

Dr. Dan Roberts, Chair, Department of Medicine, University of Manitoba

Dr. Marianne Krahn, Oncology Administration, St.Boniface Hospital

Pierrette Saulnier, President, Pastoral Council, St. Eugene R.C. Church

Prof. John Bond, Department of Family Studies, University of Manitoba

Ms Maris Webster, Winnipeg

Ms Gloria Dixon, Department of Social Work, Misericordia Health Centre

Kris Metcalfe, Red River Community College

Jocelyn Downie, Health Law Institute, Dalhousie University

Martha Jackman, University of Ottawa

Tim Caulfield, Director of Research, Health Law Institute, University of Alberta

Ian Toal, R.N., Winnipeg

Dawn Dudley Oosterhoff, Faculty of Law & Joint Centre for Bioethics, University of Toronto

Sylvia Furch Rothney, Executive Director, Alzheimer Society of Manitoba

Dr. Paul Henteleff, Winnipeg

Marilyn Dupré, Social Worker, Winnipeg

Bjorn Christianson, Q.C., Portage la Prairie, MB

Dr. T. Wright, Campbellville, ON

Mary Holmen, Chair, Ethics Committee, Selkirk Mental Health Centre

Ms Chris Eichkorn, Catholic Health Association of Manitoba

Ursula Remillard, Mission & Pastoral Care Director, St. Amant Centre

Don Logan, Winnipeg

Erica Stone, practising lawyer, Ottawa, ON

Shannon Pidlubny, Health Systems Analyst, Regional Policy and Intergovernmental Affairs, Health Canada

Joanne Thibault, Winnipeg

Ms Deborah J.M. Palumbo, Senior Policy Advisor, Office of the Leader of the Government in the Senate and Minister with Special Responsibility for Palliative Care, Ottawa

Ray J. Racette, President and Chief Executive Officer, Victoria General Hospital Bioethics Committee

Vera Derenchu, Chairperson, Victoria General Hospital Bioethics Committee

APPENDIX C

COLLEGE OF PHYSICIANS AND SURGEONS OF MANITOBA
SAMPLE POLICY
WITHHOLDING AND/OR WITHDRAWING
LIFE-SUSTAINING TREATMENT

BACKGROUND

The relationship between physician and patient is based on the ethical principles of justice, beneficence, non-maleficence and respect for patient autonomy. The primary goal of medical treatment is to restore or maintain patient health as much as possible, maximizing benefit and minimizing harm.

Patients, their families, substitute decision makers and health care providers require a supportive environment in which to address issues relating to end of life care. The term family as it is used throughout this Policy includes those who are closely linked to a patient in knowledge, care and affection and may include not only biological family and those linked to a patient by marriage, but may also include a patient's family by choice.

Physicians have a responsibility to consult with their patients or substitute decision makers, and where appropriate, their patients' families, regarding either withholding or withdrawing life-sustaining treatment and to attempt to facilitate a consensus on how to proceed.[1] Approaches towards reaching a consensus and/or managing conflict need to be tailored to the particular concerns and circumstances of each patient and will require physicians to use their best clinical and ethical judgment. Physicians should recognize that decisions concerning life-sustaining treatment may need to be revisited as patient circumstances change.

This Policy sets out a process-based approach to making these decisions and sets the parameters within which these decisions should be made. It focuses on conflict resolution when life-sustaining treatment is sought and a physician believes that it is medically inappropriate for the patient.

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[1] Article 17, Code of Conduct.

The approach recognizes:

1. the right of patients or substitute decision makers and, where appropriate, patients' families to participate in decisions regarding life-sustaining treatment; and
2. physicians' integrity and autonomy by providing a basis for physicians to refuse to provide life-sustaining treatment when they determine that it would be medically inappropriate to do so.

The spectrum of clinical scenarios raising consideration of withholding and/or withdrawing life-sustaining treatment ranges from abstract discussions about potential end of life circumstances[2] to unforeseen medical emergencies[3]. There will be varying degrees of possible patient or substitute decision maker participation and/or the involvement of families across the spectrum; however, the principles outlined herein apply to all decisions to withdraw or withhold life-sustaining treatment. While the manner in which the requirements will be met may vary as necessary to accommodate unique circumstances, the process followed must adhere to the requirements as closely as possible in each case.

SCOPE

This Policy applies to all physicians.

POLICY

A. The *Most Responsible Physician*

The identity of "*most responsible physician*" must be clearly communicated to all members of the health care team, the patient or substitute decision maker and, where appropriate, the patient's family, and must be documented in the patient's medical record.

The *most responsible physician*:

1. is the coordinator of the patient's clinical care;
2. is the person to whom the patient or substitute decision maker and/or family members and other health care providers look for direction and dialogue;
3. serves as a consistent clinical presence, even when consultants or other health care providers may be variably involved; and
4. is not necessarily the clinician with the most expertise, but rather the one with the most meaningful ongoing relationship with the patient, by virtue of history, circumstance, relationship, or request.

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[2] e.g. . consulting with a patient in the course of preparing a Heath Care Directive or regarding an advanced care plan to address anticipated end of life situations in the course of treatment of a chronic condition.

[3] e.g. ceasing resuscitative efforts following a cardiac or respiratory arrest resulting from an unforeseen event such as an accident or the sudden onset of an acute condition.

For a patient admitted to a health care facility such as a hospital or personal care home, it is the responsibility of the physician identified on the chart addressograph or database to either act as the *most responsible physician*, or to clearly designate another willing physician as the *most responsible physician*. For a patient in an emergency department or intensive care unit, the *most responsible physician* may be the emergency room physician or intensive care physician in urgent situations, but may often be the family physician or a specialist who has assumed care of the patient. Ultimately, it is the responsibility of the emergency department or intensive care unit staff to be aware of the identity of the *most responsible physician* for a given patient under their care. For patients in the community, the *most responsible physician* is either the patient's family physician, or the specialist who has taken primary responsibility for ongoing medical care due to the complexity of the case.

When a physician is confronted with a clinical scenario in which withholding or withdrawing a life-sustaining medical intervention may be appropriate, where that physician is not the patient's *most responsible physician*, the physician should consult with the *most responsible physician*, if possible. Otherwise, that physician should assume the role of the *most responsible physician* or find someone who will.

B. Prognosis and Treatment Options

The *most responsible physician*, in consultation with other members of the health care team, should consider the range of medically appropriate treatments for the patient, including those that are life-sustaining interventions that may be withheld or withdrawn. In assessing the patient's prognosis and the treatment options, the *most responsible physician* must rely on the best available clinical evidence, including, where appropriate, consultation with a specialist[4].

Where the *most responsible physician* is uncertain and/or is ambivalent about any aspect of the range of medically appropriate life-sustaining treatment for the patient, prior to reaching a conclusion as to what form of treatment is most medically appropriate for the patient, the *most responsible physician* must seek additional clinical input:

1. where possible, from other health care team members, such as another physician involved in the patient's care, and/or
2. by consulting with at least one other physician, preferably inside the same institution, or if not available;
3. by consulting with a physician outside the institution by telephone.

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[4] Recognize your limitations and the competence of others and when indicated, recommend that additional opinions and services be sought. Article 6, Code of Conduct.

C. Consultation with the Patient or Substitute Decision Maker and/or Family

Patient

Where the range of medically appropriate treatments involve the possibility of withholding or withdrawing life-sustaining treatment, the *most responsible physician* must, as early as possible and where possible, while the patient is competent and capable of participating in the discussion, consult with the patient regarding the patient's prognosis and wishes for treatment. In the case of many chronic diseases likely to result in eventual deterioration of health and death, timing of initiation and the extent of such discussions will depend on many factors, including the personal circumstances of the patient, and will involve the exercise of clinical judgment by the physician.

Substitute Decision Maker

Where the patient is not competent to make decisions regarding care, the *most responsible physician* must, as early as possible and in consultation with others where appropriate, identify the patient's substitute decision maker.

If the patient has a health care directive appointing a health care proxy, the *most responsible physician* must accept the appointment as expressed in the directive. Where the directive identifies a health care proxy, the proxy will be the patient's substitute decision maker.

Where there is no health care directive and/or proxy, the *most responsible physician* must ascertain the identity of the person with legal authority to make decisions on behalf of the patient and that person will be the patient's substitute decision maker. Depending on the circumstances, the substitute decision maker may be a family member, legal guardian, court appointed committee or other party such as the Public Trustee. The physician must consult with the substitute decision maker in the same way as the physician would otherwise consult with the patient.

Consultations

In consultation with the patient or the substitute decision maker, the *most responsible physician* must attempt to reach a consensus on how to proceed. The consultations with the patient and/or substitute decision maker should include:

- with the assistance of patient or substitute decision maker, identification of others who should be involved in the discussion, and, where possible, accommodating the participation of anyone identified in the discussion;
- an inquiry as to the patient's personal, cultural and family issues that may impact on the decision, such as their existing knowledge, awareness and understanding of the patient's condition and treatment options and their interest in pursuing treatment

options;

- a description of the nature of the underlying condition or ailment;
- the options for treatment and their expected outcome;
- the prognosis with or without medical intervention in the form of life-sustaining treatment;
- the reason why the physician feels that initiating or continuing life-sustaining treatment may be medically inappropriate;
- options including palliative care and hospice care where applicable;
- assurances that the patient will not be abandoned in the event that medical intervention is either withheld or withdrawn;
- confirmation that other forms of medical treatment such as palliative care measures which emphasize patient comfort and dignity will be provided;
- where the *most responsible physician* recommends either withholding or withdrawing life-sustaining treatment and the recommendation is not accepted, an exploration of the reasons why the patient or substitute decision maker wishes treatment to be continued and address these issues directly with a view to resolving them, including, where appropriate:
    1. a description of the decision making process, including the information that the physician has the responsibility to recommend and provide only those treatments that the physician determines are medically appropriate for the patient;
    2. exploring feelings of guilt that may exist and addressing fears that those involved in the decision are causing the patient's death by agreeing with a recommendation that life-sustaining treatment be withheld or withdrawn;
    3. among the solutions offered, offering a time-limited trial of therapy with clear predefined outcome goals to accommodate either medical issues or satisfy personal concerns of patient, substitute decision maker, the patient's family or others;
    4. mutually agreeing to take any additional or alternative steps to facilitate a consensus, including, but not limited to, involving institutional resources such as a patient advocate, mediator, ethics committee or institutional review process;
    5. an offer of institutional resources such as social work, chaplaincy, or bioethics to assist the patient or substitute decision maker or family with their psychosocial, cultural, spiritual, and informational needs;
- documentation of the pertinent details of this communication in the patient's health record.

If a consensus results from the consultation with either the patient or the substitute decision maker, the decision can be implemented without the consent of the patient's family or others, but if a medical intervention is to be withheld or withdrawn, the *most responsible physician* should, with the consent of the patient or substitute decision maker, attempt to communicate with the family members and fully explain the reasons for the decision.

D. Additional Clinical Input

If consensus cannot be reached as a result of the consultations referred to above, the *most responsible physician* must address with the patient or substitute decision maker the option of the patient or substitute decision maker's obtaining an independent medical opinion concerning the medical appropriateness of the intervention in question and facilitating a request for an independent medical opinion by providing all relevant medical information to the consultant chosen by the patient or substitute decision maker.

E. The Most Responsible Physician's Onus to Decide

Where the patient is not competent and it is not reasonably possible to consult with the substitute decision maker, the onus is on the *most responsible physician* to decide whether or not life-sustaining treatment should be withheld or withdrawn. When a physician is confronted with making such a decision without the input of the patient or someone to whom the authority to represent the interests of the patient has been delegated, the onus is on the *most responsible physician* to make the decision based on his/her determination of what is in the best interests of the patient[5]. In such circumstances, the *most responsible physician* should consider consulting with other members of the health care team, including another physician in reaching a decision. The *most responsible physician* should communicate the decision to other members of the health care team as soon as possible after the decision has been made.

F. Transfer of Care

The *most responsible physician* must, where possible, provide the patient or substitute decision maker with an opportunity to identify another physician willing to assume care of the patient and facilitate the transfer at any time when the patient or substitute decision maker requests that the patient's care be transferred to another physician who is willing to assume care of the patient.

G. Impasse – Notice of Decision

If, despite all reasonable efforts, a consensus cannot be reached, the *most responsible physician* must, where possible, provide at least 72 hours notice to the patient or substitute decision maker, preferably in writing, prior to withholding or withdrawing life-sustaining treatment.

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[5] What is in the best interests of the patient will depend on each individual patient. Decisions should be justifiable in terms of providing an overall health benefit to the patient. In determining what is in the patient's best interests, the *most responsible physician* should take into account relevant information that may impact on the decision, such as what is medically appropriate and what was the patient's understanding of the condition and treatment options and desire to pursue treatment, as well as any social, cultural, and/or spiritual issues of which the *most responsible physician* is aware.

H. Withholding or Withdrawal of Life-sustaining Treatment

The *most responsible physician* may withhold or withdraw life-sustaining treatment, or authorize other members of the health care team to withhold or withdraw life-sustaining treatment, including intensive care:

1. with the consent of the patient or substitute decision maker at any time;

2. without the consent of the patient or substitute decision maker:

   i) where the *most responsible physician* has otherwise complied with all of the requirements of this policy **and**
      a) the *most responsible physician* believes that it is medically appropriate for the patient, **and**
      b) the *most responsible physician* is unable to obtain consent because the patient is not competent, **and**
      c) it is not possible to consult with the substitute decision maker;

   OR

   ii) where consultation with the patient or substitute decision maker has not resulted in consensus:
      a) **after** the notice period has elapsed, **and**
      b) in the absence of a transfer of the patient's care to another physician **or** the initiation of legal steps to prevent the treatment from being withdrawn or withheld at any time during the notice period.

APPENDIX D

ADVANCED CARE PLANNING PROTOCOL OF THE WINNIPEG REGIONAL HEALTH AUTHORITY

EXHIBIT "B"

Draft Dec. 7, 2002

ADVANCE CARE PLANNING

Background:

The following are among the current options in helping to define "end of life" care at WRHA hospitals and Personal Care Homes:

- **Health Care Directives** made in accordance with Manitoba's *Health Care Directives Act*. These can only be made by persons 16 years of age or older, who are legally competent. Such a person may name a "proxy". Caregivers are in general required, to the best of their abilities, to follow instructions contained in Health Care Directives.

- **Levels of Intervention**, currently in existence at most Winnipeg hospitals and Personal Care Homes. In general, they are created where residents, patients, proxies, substitute caregivers, families, or facilities wish to define care in anticipation of deterioration. While they must be consistent with any existing health care directives (as described above), they do not replace them and cannot contravene them. Although all WRHA acute and Long Term Care facilities generally have such "level of intervention" forms and processes, they may vary in their descriptors of "levels", and in the elements of the process.

Over a year ago, concern was expressed at the lack of consistency among site "level of intervention" forms and processes. In addition, existing Winnipeg Fire Paramedic Service policies requiring mandatory resuscitation have prevented their respecting any "levels of intervention" other than full resuscitation, when they transfer patients between WRHA facilities (except when care plans are clearly identified as "health care directives"). An opportunity therefore exists to improve continuity of end of life care if inconsistencies in the forms and processes among sites can be addressed, and Winnipeg Fire and Paramedic Service policies can be influenced. There could then be a consistent and widely understood regional approach to high quality patient-centered end-of-life care. Standardizing the definitions and processes would also reduce confusion for physicians who attend at multiple sites and are therefore forced to deal with different "levels of intervention" forms and processes.

In response to the above, the WRHA has adopted the concept of "advance care planning". A standardized "advance care plan" tool and process would then be available at each Winnipeg

Regional Health Authority facility. These would replace site specific "level of intervention" forms and processes currently utilized, while accommodating site specific cultures and values wherever possible. The new terminology of "advance care plan, or planning" helps to highlight the emphasis on the voluntary, collaborative planning process rather than the form itself. The "form" is only completed after a process of education, discussion, reflection, with regular revisiting. The "form" is meaningless without this process.

Pauls et al (J. Emergency Med. Vol. 21, No. 1, pp. 83-89, 2001) describe the necessary attributes of the process of *advance care planning*:

- Education sessions, using a variety of approaches and resources
- The focus of sessions is information sharing, not form completion
- Review forms regularly, and with any change in health status
- Involvement of a variety of health care providers in the sessions
- Complete forms in advance of acute illness, where possible
- Forms to be kept in a consistent, accessible location
- Regional implementation
- Obtain endorsement of regulatory and licensing authorities
- Develop mechanisms to hold providers accountable if the forms are not followed
- Encourage direct communication among health care providers
- Improve provider education about the process.

The phrase *advance care planning* is more reflective of the discussions, education, and consultations that ought to occur when dialogue concerning end-of-life care is deemed relevant.

Unlike the case of *health care directives,* persons younger than 16 years of age can participate in the formulation of *advance care plans.*

It is important to note that an *advance care plan* must be congruent with any existing health care directive; an *advance care plan* is not a *health care directive,* but could become one if an individual so wishes and if the individual is competent. To underscore the fact that an *advance care plan* is neither a *health care directive,* nor has legal authority, patient/proxy/substitute decision-maker signature is not required. The healthcare provider simply documents the discussion and the consent that was verbally communicated. This in no way minimizes the key role of the patient/proxy/substitute decision-maker in collaborating with providers to negotiate a treatment plan (i.e. *advance care plan*). Hopefully, the omission of the signature will help eliminate any confusion that might exist between an *advance care plan* and a legally recognized *health care directive* that must be signed (by a competent individual).

Where patients/residents fall under the Public Trustee, but are able to engage in *advance care planning,* the Public Trustee should be forwarded a copy of the proposed plan, for the information of the Public Trustee.

There has been wide dissemination of this initiative through the acute and long term care community, and consultation with the ethics community. It is hoped that Winnipeg Fire Paramedic Services, and stretcher transport service providers, can develop supporting policies and practices.

While consensus on all aspects and details may not be achievable, there is a general agreement that "*advance care planning*" as described is preferable to the present situation.

Only when hospitals, Personal Care Homes, Palliative Care services, and ambulance and transport services are thus connected and convergent, in terms of end of life care provision, can Winnipeg residents be assured of high quality end of life care.

Implementation:

Implementation of this project, which must be viewed as a quality of care issue, will begin in early 2003. This initiative will be regionally phased in through application to new admissions to hospitals and personal care homes, where appropriate. Broader community application will be considered thereafter.

Facilities will oversee their own implementation, assisted by the creation of some common educational resources developed by a regional "implementation committee" which includes an ethicist, two or three selected clinicians and other health professionals. This committee would offer an appropriate presentation on both process and content of *advance care plans* to key health care providers at each site. Having participated in staff development and education, these site leaders would then be charged with the responsibility of disseminating information throughout the site. Site stakeholders would include medicine, nursing, speech and language pathology, pastoral care, social work, patient relations, and possibly others. An added advantage to this model would be the opportunity to create linkages between personal care homes and the ethicists on the "implementation committee". Although there is already an ethics presence in hospitals, this is not usually the case in the personal care home system.

Community forums hosted by the WRHA and attended by members of the "implementation committee" are also recommended. These would have several purposes:

- Increase public awareness around end of life issues
- Entertain dialogue and feedback as part of the evaluative process
- Engage specific publics (e.g. persons with disabilities, seniors, etc.) that might wish to contribute to the ongoing discussions.

Evaluation will occur after a one-year period. It will consist of audits and other tools to identify:

- Facility compliance with process (through review of policy)
- Access of residents or patients in a given facility to "advance care planning"
- Statistics from EMS
- Qualitative data from WRHA staff, EMS staff, and specific publics
- Adequacy of content and process
- Patient/resident satisfaction/dissatisfaction/feedback.
- Others yet to be determined.

Recommendations to continue, revise or reject the *advance care plan* project would be made, based on the results of this evaluation.

WRHA Advance Care Plan

Date: ____________________

Name: ____________________

Date of Birth: ____________________

Residence/facility: ____________________

PHIN: ____________________

Diagnosis:

____

____

____

Context for Completion of this Document:

An *advance care plan* represents a summary of discussions with patients/residents and/or identified substitute decision-makers regarding specific health and/or life issues. It is to be used to communicate the preferences, values and beliefs of a patient/resident regarding treatment and care. As patients/residents are the primary decision-makers with respect to their treatment and care, direct quotes reflecting the person's preferences, values, beliefs may be instructive.

Examples:

1) Has end stage heart disease, not a surgical candidate. Wishes a peaceful death with no aggressive end-of-life interventions. Wants any discomfort treated aggressively. Very afraid of being "kept alive on a ventilator".
2) "I am the proxy for my elderly parent, who is demented, and has an extremely poor quality of life. I don't want any serious illness treated, even if reversible, but I don't want there to be any suffering."
3) "I have had 5 heart attacks and I don't want my heart restarted if it stops, for any reason. However, if I develop some other condition that has nothing to do with my heart, I want all other treatment."

An *advance care plan* must be completed in consultation with:

- the patient/resident if competent. In law, competence is presumed (but may be rebutted by evidence to the contrary), providing the individual is 16 years of age or older. If decision-making capacity is questioned, this should be formally assessed.
- An identified substitute decision-maker if the patient/resident lacks decision-making capacity.

On-going conversation between patients/residents and health care providers is the primary route to establish mutually understood and agreed upon *advance care plans*. The *advance care plan* form is not a substitute for the discussions between patients/residents and health care providers which must occur in order to complete the form.

Provide "context" as described previously:

____

____

____

____

____

____

____

____

Is there an existing *health care directive*. (Circle answer) **YES** **NO**
If yes, a copy must be attached to this document, and if the patient/resident is not competent and a proxy has been named, the proxy must be consulted in the development of an *advance care plan*. If the patient/resident is competent and a proxy has been named in a health care directive, consideration should be given to having the proxy participate in the development of any *advance care plan*.

Remember that an *advance care plan* is not the same as a *health care directive*. The latter is ideally "self-initiated" and carries certain legislated authority, while the former is "system or facility-initiated", always negotiated, and not legally binding. It does not require the signature of the patient/resident/proxy/substitute decision-maker. However, the content of any *advance care plan* must always be consistent with any existing *health care directive*.

An advance care plan must reflect diagnoses and context, and must operationalize any existing *health care directive*. Any change in diagnoses, context, or *health care directive* must result in a revisiting of the *advance care plan*. Finally, each of the following plan choices obviously requires attending physician acceptance, since a physician cannot be compelled to provide treatments that he or she, in good conscience believes to be futile, or not in the best interests of the patient/resident. When consensus concerning an *advance care plan* has not been reached, further discussions, and second opinions should be considered. **Failure to achieve general consensus must result in abandonment of the use of this form. In this case, clinician decisions made in the face of patient/resident or substitute decision-maker opposition must be reflected on the order sheet rather than this form.**

Advance Care Plan 1:
This is often referred to as palliative or comfort care. It focuses on aggressive relief of pain and discomfort. There is no CPR (intubation, assisted ventilation, defibrillation, chest compressions, advanced life support meds). There are also no lifesustaining or curative treatments such as ICU, tube feeds, transfusions, dialysis, IV's and certain medications. All available tests and treatments necessary for palliation are done, including medications and transfer to hospital if necessary.
(comfort care/no treatment of nonreversible and reversible conditions/no CPR)

Advance Care Plan 2:
This provides palliative and comfort care as above, but also allows for treatment of reversible conditions (e.g. pneumonia, blood clot) that may have developed. There is no CPR (intubation, assisted ventilation, defibrillation, chest compressions, advanced life support meds). ICU, all available tests and treatments for reversible conditions are offered, based on medical assessment, except for CPR. You may elect to refuse certain tests and treatments for any reversible condition, based on your values (e.g. tube feeds, dialysis, ICU, transfusions, IV's, certain medications, certain tests, transfer to hospital, etc.) If you wish to refuse certain tests and treatments of your reversible condition, please list them:

____

(comfort care/no treatment of nonreversible cond./treatment of reversible cond./no CPR)

Advance Care Plan 3:
This provides any necessary palliative and comfort care as above, plus available treatment of all conditions, both reversible and nonreversible, with no restrictions, except for CPR. There is no CPR (intubation, assisted ventilation, defibrillation, chest compressions, advanced life support meds). As above, you may elect to refuse any tests or treatments for both your nonreversible and your reversible conditions. If so, please list them:

____

(comfort care/treatment of nonreversible and reversible conditions/no CPR)

Advance Care Plan 4:
This level provides for all available treatment of all conditions, and includes full CPR.
(comfort care/treatment of nonreversible and reversible conditions/full CPR)

The chosen advance care plan is (1, 2, 3, or 4): ____________.

Qualifiers:

____.

(Transcribe this information to the order sheet)

Reminders:

- If a *health care directive* exists, the *advance care plan* chosen above must be consistent with it.
- If the patient/resident is a ward of the Public Trustee, and is competent to engage in *advance care planning*, the Public Trustee should be provided with a copy of this.

Health provider signature: ____
(This is only signed if the plan has been developed in collaboration with a provider other than the responsible physician. The signature acknowledges the processes of *advance care planning* have been respected, and that the plan reflects the intended goals.)
Printed Name: ____

Date: ____________________________________

Responsible physician signature:____

(This signature acknowledges understanding of the *advance care planning* process, and support of the goals of the selected plan.)

Printed Name: ____

DATE: ____________________________________

This document must be reviewed (and initialed) every year, or as necessary with any clinical change, or at the request of the patient, proxy, substitute decision maker, or any member of the treatment team, or with creation of, or change in a *health care directive*.

REVIEW
DATES:____

EXECUTIVE SUMMARY
OF
REPORT ON
WITHHOLDING OR WITHDRAWING LIFE SUSTAINING MEDICAL TREATMENT

A. INTRODUCTION

In June 2002, the Manitoba Law Reform Commission released a discussion paper entitled *Withholding or Withdrawing Life Sustaining Treatment,* which is appended to the Report. It explores a range of issues relating to end of life medical decision-making including: the power of modern technology to prolong life beyond its natural end; the propriety of providing life sustaining medical treatment which offers no therapeutic benefit and may threaten additional harm; the competing interests of patients, physicians and other stakeholders; the allocation of ultimate authority for making decisions to withhold or withdraw life sustaining medical treatment; and the principles and procedures that should guide the decision making process.

The Report outlines the policies and procedures that should guide end of life decision making and contains our recommendations on how best to implement that protocol.

B. PRINCIPLES AND POLICIES

The Commission believes that there are certain fundamental principles and policies that should be reflected in the rules or framework controlling the withholding or withdrawal of life sustaining medical treatment.

1. There must be a uniform approach and process to withholding or withdrawing life sustaining medical treatment across the province and in all health care institutions.

2. The uniform approach must apply to all decisions to withhold or withdraw life sustaining medical treatment whether in the form of Do-Not-Resuscitate (DNR) orders or other decisions.

3. The uniform approach must treat all citizens fairly and equitably and provide equal access to medically appropriate medical care to all without bias or favour. In particular equal treatment must extend to the elderly and persons with disabilities. Neither of those circumstances is a sign of terminal illness or impending death.

4. The decision making process must be clear and transparent and must be communicated

clearly not only to the patient and his or her family but also to the public in order to facilitate a broad understanding of how these decisions are made.

5. Emphasis must be placed on the *process* for decision making rather than the formulation of specific rules which would purport to dictate the decision. The process must be designed to facilitate an *agreement* between the physician and the patient or his or her substitute decision maker. It should have the following features:
   - the process should be instigated by the attending physician;
   - the process should begin at the earliest appropriate time to provide an opportunity for considered and informed discussion and decision-making;
   - full and complete information must be provided by the attending physician to the patient/substitute decision maker about the nature of the patient's condition, prognosis, treatment options (including those that the physician may not favour) and the expected benefit or harm of those options;
   - a full and complete explanation by the attending physician why he or she believes that withholding or withdrawal of life sustaining medical treatment is medically appropriate;
   - a full and complete discussion between the attending physician and the patient of his or her personal, cultural circumstances and spiritual beliefs and concerns insofar as they are relevant to the decision at hand and welcomed by the patient;
   - a full and complete discussion between the attending physician and the patient of his or her wishes, concerns, expectations and preferred treatment options including consideration of a time limited trial of therapy;
   - a full consultation with the family of the patient unless such communication is prevented for some documented reason such as impracticality, breach of privacy or confidence;
   - full information and assurances to the patient that a withdrawing of withholding of life sustaining medical treatment does not amount to an abandonment of care and compassion and that palliative treatment will be provided.

6. Where a consensus cannot be reached between the physician and the patient or substitute decision maker about withholding or withdrawing life sustaining medical treatment resort should be had to other available informal dispute resolution procedures. Institutional facilitators and mediators such as ethicists, pastoral care workers and other qualified persons can assist in finding a consensus between the physician and the patient or substitute decision maker. In some circumstances, independent external mediators may be helpful. Every reasonable effort should be used to secure agreement in as informal and sensitive a process as possible.

7. Where there is disagreement between the physician and the patient or substitute decision maker on the appropriate course of action, the patient must be given an opportunity to secure an independent second opinion from a physician who is not a member of the patient's health care team and/or request that his or her care be transferred to another willing physician.

8. Where all preceding measures have failed to produce an agreement, the physician may, after an appropriate notice period, withhold or withdraw life sustaining medical treatment where such treatment would be medically inappropriate.

9. We do not favour a right to indefinite life sustaining medical treatment. The appeal of autonomous decision making and personal control of all end of life medical decision making is initially attractive but an unfettered right to life sustaining treatment may result in unreasonable demands being made for indefinite inappropriate medical treatment.

10. Final resort to the courts will remain available where the procedures designed to achieve consensus have irretrievably broken down.

C. IMPLEMENTATION

The Commission does not favour a legislative implementation of these principles. Its preference is to see them embodied in a statement or by-law of the College of Physicians and Surgeons of Manitoba. It has, indeed, been drawn to our attention that the College is developing a new protocol for end of life decision making and we have studied its sample *Proposed Policy on Withholding or Withdrawing Life-sustaining Treatment.* The policy reflects many of the principles for end of life decision making that we have described. We have therefore devoted much time and attention to that sample policy and have recommended changes that would further emphasize and promote our views. We also recommend that other health care institutions, agencies, associations and bodies involved in delivering health care in Manitoba should adopt the Policy of the College once amended to reflect our advice. We urge them to use the Policy as a template for their own protocols and procedures.

We envisage a cohesive and integrated approach to maximize consensus decision making without imposing an obligation on physicians to provide inappropriate medical care. Such an approach, coupled with an extensive program of public education and awareness of the end of life decision making process, will serve the citizens of Manitoba well.

RAPPORT SUR LA RESTRICTION OU LE RETRAIT DE TRAITEMENTS MÉDICAUX DE SURVIE

RÉSUMÉ

A. INTRODUCTION

En juin 2002, la Commission de réforme du droit du Manitoba a publié un document de travail sur la restriction ou le retrait de traitements médicaux de survie (*Withholding or Withdrawing Life Sustaining Treatment*), que nous avons joint au rapport. Ce document examine toute une série de questions ayant trait aux décisions médicales concernant la mort, notamment : la capacité de prolonger la vie au-delà de ses limites habituelles, grâce à la technologie moderne; la légitimité de prodiguer des soins médicaux afin de maintenir une personne en vie quand ces soins n'ont aucun avantage thérapeutique et pourraient même présenter plus de dangers; les intérêts opposés des patients, des médecins et des autres parties concernées; la délégation d'autorité pour prendre la décision finale relativement à la restriction ou au retrait d'un traitement médical de survie; et les principes et procédures qui devraient guider tout processus décisionnel.

Le rapport donne un aperçu des politiques et procédures qui devraient guider les décisions médicales concernant la mort et présente nos recommandations sur la meilleure façon de mettre celles-ci en œuvre.

B. PRINCIPES ET POLITIQUES

La Commission croit qu'il existe certains principes et politiques fondamentaux qui devraient être reflétés dans les règles ou dans le cadre autorisant la restriction ou le retrait de traitements médicaux de survie.

1. Il faudrait adopter une approche et un processus uniformes en ce qui concerne la restriction ou le retrait de traitements médicaux de survie, à l'échelle de la province et dans tous les établissements de soins de santé.

2. Cette approche doit s'appliquer à toutes les décisions prises relativement à la restriction ou au retrait de traitements médicaux de survie, qu'il s'agisse d'ordonnances de ne pas réanimer (DNR) ou d'autres décisions.

3. Cette approche doit permettre de traiter tous les Manitobains et Manitobaines raisonnablement et équitablement et d'offrir à chacun et à chacune le même accès aux soins

médicaux appropriés, sans discrimination ni favoritisme. Ce traitement équitable doit s'appliquer tout particulièrement aux aînés et aux personnes handicapées, ces deux groupes de personnes n'étant pas dans une situation synonyme de maladie terminale ou de mort imminente.

4. Le processus décisionnel doit être clair et transparent et doit de plus être expliqué clairement non seulement au patient et à sa famille, mais aussi au public afin que le plus grand nombre de personnes possibles comprenne la manière dont ces décisions sont prises.

5. Il faut mettre l'accent sur le *processus décisionnel* plutôt que sur la formulation de règles particulières qui permettraient d'arrêter la décision. Le processus doit être conçu de manière à favoriser une *entente* entre le médecin et le patient ou son subrogé. Pour ce faire, le processus décisionnel devrait :

- être amorcé par le médecin traitant;
- être déclenché le plus tôt possible et à un moment approprié afin de laisser aux personnes concernées le temps de mûrement réfléchir, d'avoir des discussions éclairées et de prendre les décisions qui s'imposent;
- obliger le médecin traitant à fournir au patient ou à son subrogé des renseignements complets sur l'état de santé du patient, son pronostic, les options en matière de traitement (y compris les interventions qui vont à l'encontre de l'avis du médecin), ainsi que les résultats escomptés ou les répercussions négatives des différents traitements (le cas échéant);
- inclure une explication complète de la part du médecin traitant indiquant pourquoi il croit approprié de refuser ou d'interrompre le traitement médical de survie;
- comprendre une discussion détaillée et complète entre le médecin traitant et le patient relativement aux circonstances personnelles et culturelles, aux croyances religieuses et aux préoccupations de ce dernier, et ce, dans la mesure où celles-ci influeraient sur la décision à prendre et seraient bien accueillies par le patient;
- comprendre une discussion détaillée et complète entre le médecin traitant et le patient afin de connaître les désirs, préoccupations, attentes et choix de traitement préférés de ce dernier, y compris la possibilité de suivre une thérapie pendant une période déterminée;
- inclure un entretien approfondi avec la famille du patient sauf si cela est interdit en raison d'une exigence documentée (p. ex. un tel entretien ne serait pas pratique ou constituerait un abus de confiance ou une atteinte à la vie privée du patient);
- permettre au patient d'avoir accès à des renseignements complets et de recevoir l'assurance que même si le traitement médical de survie est refusé ou interrompu, il recevra toujours des soins prodigués avec compassion et le traitement palliatif nécessaire.

6. Lorsque le médecin traitant et le patient ou son subrogé ne sont pas d'accord pour refuser ou interrompre un traitement médical de survie, ils devraient recourir à un autre type de procédure informelle afin de régler leurs différends. Un facilitateur ou un médiateur de l'établissement de soins, comme un service de pastorale, un comité de bioéthique ou

d'autres personnes qualifiées pourraient aider les parties concernées à trouver un consensus. Dans certaines situations, il pourrait s'avérer utile de recourir à un service de médiation externe. Il faut tout mettre en œuvre pour que les parties concernées arrivent à s'entendre, et ce, de la manière la plus simple et sensible possible.

7. Lorsqu'il y a un différend entre le médecin traitant et le patient ou son subrogé sur le plan d'action à suivre, il faut donner au patient la possibilité de demander conseil auprès d'un autre médecin ne faisant pas partie de l'équipe soignante ou de demander à ce qu'un autre médecin consentant s'occupe de son cas.

8. Lorsque toutes les procédures précédentes ont échoué, le médecin traitant pourrait, après une période de préavis appropriée, refuser ou interrompre le traitement médical de survie, s'il juge celui-ci inapproprié sur le plan médical.

9. Nous ne voulons pas reconnaître le droit de faire appel à des traitements médicaux de survie pour une durée illimitée. Au premier abord, il pourrait sembler attrayant de disposer d'un processus décisionnel autonome et de laisser aux gens le soin de prendre leurs propres décisions en matière de traitements en fin de vie, mais la possibilité d'avoir un recours illimité aux soins médicaux de survie pourrait créer des demandes déraisonnables de traitements médicaux inappropriés et à durée illimitée.

10. Il restera la possibilité de recourir aux tribunaux quand tous les moyens mis en œuvre pour atteindre un consensus ont abouti à un échec total.

C. MISE EN ŒUVRE

Les membres de la Commission ne tiennent pas à ce que ces principes soient mis en œuvre grâce à des mesures législatives. Ils préféreraient qu'ils soient incorporés dans un énoncé ou dans un règlement formulé par le Collège des médecins et chirurgiens du Manitoba. Nous savons que le Collège élabore actuellement un nouveau protocole relativement à la prise de décisions en fin de vie et avons étudié l'ébauche intitulée *Proposed Policy on Withholding or Withdrawing Life-sustaining Treatment* (politique proposée sur la restriction ou le retrait des traitements médicaux de survie). Cette politique comprend bon nombre de principes relatifs à la prise de décisions en fin de vie qui sont similaires à ceux que nous avons décrits plus haut. Nous avons donc consacré beaucoup de temps et de soins à étudier cette ébauche et avons suggéré des changements qui permettraient de souligner et de promouvoir davantage nos points de vue. Nous recommandons aussi que les autres établissements, organismes, associations ou organisations offrant des soins de santé au Manitoba adoptent les politiques du Collège une fois que celles-si auront été modifiées en fonction de nos recommandations. Nous demandons avec instance qu'ils utilisent ces politiques comme guide pour l'élaboration de leurs propres protocoles et procédures.

Nous envisageons une approche cohésive et intégrée qui favorisera une prise de décisions par consensus, de manière que les médecins ne soient pas obligés de fournir des soins médicaux inappropriés. Une telle approche, combinée à un vaste programme d'éducation et de sensibilisation du public relativement au processus décisionnel en fin de vie, sera dans l'intérêt de tous les Manitobains et Manitobaines.